Learning disabilities and behaviour that challenges: service design and delivery

Consultation on draft guideline - Stakeholder comments table
09/10/2017 to 20/11/2017

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Stakeholder	Document	Page No	Line No	Rec	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
2Gether NHS Foundation Trust	Short	12	22	1.2.9	We believe that Case Management (Social Care assessment and monitoring associated with funding) needs to be differentiated from Care-Coordination in health. They are not the same function and are likely to require different coordinators with different skill sets. Both functions are necessary but in our experience are unlikely to sit best within the remit of a single professional.	Thank you for your comment. The committee considered this feedback, but felt that the evidence and the view of the committee was that the main function of the named worker should be to provide continuity and co-ordination of care, and that this person could do this from within a social care or health role. The recommendation was revised to clarify this.
2Gether NHS Foundation Trust	Short	19	17	1.4.9	We think this statement may need qualifying to suggest a 1hr response for the most critical situations. A starting point for definition of 'critical' might be Mental Health Act criteria or an indication that such response is warranted due to the risk of serious harm to the person or others	Thank you for your comment. We have revised recommendation 1.4.10 to make clearer that the response should be based on an initial 'triage', and that the response of 1 hour is for phone response only. Face-to-face response is suggested within 4 hours if required following triage and assessment.
2Gether NHS Foundation Trust	Short	20	25	1.5.1	Particular attention may need to be given to the needs of some people with autism (e.g. where there are significant sensory issues)	Thank you for your comment. This guideline addresses the needs of children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. The recommendation covers identifying the specific housing needs of this group.
2Gether NHS Foundation Trust	Short	20	6,10, 13	1.4.12, 1.4.13, 1..4.14	The word "teams" might be helpfully replaced by the word 'services'. Forensic skills and capacity need to be available but may not take the form of standalone teams	Thank you for your comment. We have used the terminology 'services' as you suggest. We have revised recommendation 1.4.12 to make it clearer that forensic services could be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning disability team.
2Gether NHS Foundation Trust	Short	21	11	1.5.6	The compatibility of people who live together is perhaps more critical than the absolute number and we would like to see this reflected here. (The clear steer towards small numbers remains helpful) . 'Where' people live should follow from a clear understanding of how they want to live and what matters to them.	Thank you for your comment. Following stakeholder feedback we have amended the wording of the recommendation to take into account your comment.
2Gether NHS Foundation Trust	Short	26	8	1.5.8	Unfortunately if an inpatient stay is required the lack of such services for children generally mean that "as close as possible to where the person usually lives" could be very far away in reality. It would be helpful to consider a statement such as "as close as possible to where the person usually lives which should normally be within 60 miles /90mins travel time".	Thank you for your comment. The wording of the recommendations follow from other recommendations on building capacity in the community, which if implemented would mean that admission to hospital will be based on clinical need and not because of a lack more appropriate services in the community. Recommendation 1.8.2 states that all other options should be considered before admission and gives the CTR and CETR and as an example of how to achieve this. The Guideline Committee discussed the meaning of "close to home" and "local", without reaching an a consensus on an understanding that could be widely understood and nationally applied, taking into account the availability of public or private transport means, rural compared to urban environments etc. To address this, recommendation 1.8.7 was revised to say that If people are admitted as inpatients outside their local area, social workers in the community learning disability team should help them stay in contact with practitioners in their own area, including their named worker.
2Gether NHS Foundation Trust	Short	28	21-24	terms	This is a widely recognised definition of 'challenging behaviour'. However, it might benefit from additional comment along the following lines: "this definition is about the nature and impact of the behaviour(s). It does not discuss causal factors which can be many and varied – these factors need to be understood to enable effective action to follow."	Thank you for your comment. We have retained the definition used by the accompanying clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), to ensure consistency. The clinical guidelines includes more detail on the factors associated with behaviour that challenges and risk of developing behaviour that challenges.
2Gether NHS Foundation Trust	Short	7	12-17	Aims and principles	This list of bullet points might benefit from a further point. ….designing and delivering services that aim to "understand and respond to the causes of the behaviour that challenges."	Thank you for your comment. The causes and factors associated with behaviour that challenges are within scope for the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have provided a reference and hyperlink to the relevant sections of the clinical guideline for more detail on evidence based approaches and responses that services should deliver.
2Gether NHS Foundation Trust	Short	8	15	1.1.3	Perhaps clarify that intention is the pooling of "certain/some" budget rather than entirety	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. Recommendation 1.1.3 states that budgets could be pooled when developing local and regional services and recommendation 1.1.5 allows for budget mechanisms having some flexibility.
Abertawe Bro	short	10	General	1.1.8	There is a need to develop a more consistent understanding of relevant outcomes and measures if service quality is to be properly assured. Quality Services should improve people's quality of life and wellbeing so the extent to	Thank you for your comment. The wording has been edited to 'restrictive interventions' to respond to your comment.

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Morgannwg Health Board					which services help people to achieve individual wellbeing and quality of life outcomes should be key. The outcome should be a reduction in the use of restrictive practices, restraint is an important element in this, but there are a range of other restrictive practices that should also be considered. Further work in these areas would fit the research priorities within a PBS framework.	
Abertawe Bro Morgannwg Health Board	short	11		general	Whilst there is nothing to disagree with in the content of his section, it would be very relevant to highlight that PBS is a person centred approach particularly concerned with enabling person-centred care for this specific population. Not to mention PBS at all in this section is a major deficit in the recommendations, and under represents established best practice in the field. Understanding why a person of any age needs to use challenging behaviour to get their needs met is a basic starting point and prerequisite for any other work. (This is what functional assessment in PBS means). The credibility of the guidance amongst the majority of stakeholders is severely undermined by this omission The role and function of the 'named worker' needs to be clearly defined, and adequately resourced. Currently, despite there widespread acknowledgement that people should have a 'care manager ' or 'care coordinator' many in reality do not. Those that do often experience great variation between the practice of care management.	Thank you for your comment. Interventions and approaches to treat, manage or prevent behaviour that challenges is in scope for the clinical guideline that accompanies this service guideline and we have provided a reference and hyperlink for people who wish to know more. Please see details as follows: (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We agree it would be helpful to have a definition of Positive Behaviour Support as we also reference the Positive Behaviour Support competencies framework in recommendations 1.9.2 and 1.9.3 and have added a definition used in the clinical guideline in the terms used section. The Guideline Committee agree that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff.
Abertawe Bro Morgannwg Health Board	short	13	24	1.2.14	Once more whilst there is nothing to disagree with in the content of his section. Improving Communication is very important and this should form part of a multi component intervention. In line 24 it would be very relevant to use the term 'implement PBS' in place of the rather vague 'and other skills'. The links to the Nice Guideline on CB & LD essentially reflect the PBS framework but do not use the term. Including the term in the current set of guidance could help address this problem which causes confusion in the field.	Thank you for your comment. This recommendation has now been edited to make clear that this phrase relates to the identification of health and sensory problems that can increase the risk of the development of challenging behaviour rather than management of the behaviour itself. Managing behaviour is the focus of the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Abertawe Bro Morgannwg Health Board	short	14	general		Personal health budgets are not available in Wales and there appears to be variation in approaches in the different countries of the UK concerning continuing health funding for this population. This highlights the need for a closer examination of the issues. Expert support from experienced and regulated social care provider agencies should also be available to individuals and families to manage budgets, employ staff, train and support them etc.	Thank you for your comment. The way NICE was established in legislation means that NICE guidance is officially England-only. Decisions on how NICE guidance applies in Wales, Scotland and Northern Ireland are made by the devolved administrations. Recommendation 1.2.20 sets out how people should be supported to manage their personal budgets, continuing healthcare budget, individual service fund or direct payment.
Abertawe Bro Morgannwg Health Board	Short	15	8	1.3.1	It's encouraging to see the term Positive Behavioural Support, being used—but it could also be used in various places in this document. PBS is very relevant across the lifespan and different settings.	Thank you for your comment. After careful consideration, we think that this is adequately covered in the references and links in these recommendations. NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the Positive behaviour support competence framework. is provided here for people to find more detailed information. We have also added a definition of Positive Behaviour Support in the term used section.
Abertawe Bro Morgannwg Health Board	Short	16	9	1.3.5	Earlier recommendations refer to the named worker having a co-ordinating role concerning support, suggesting an active role which reflects best practice. The wording here suggest a more passive advisory role only.	Thank you for your comment. This recommendation is about providing information and making sure that people understand their rights and how to access services. We have revised the recommendation to include evidencing the offers of support.
Abertawe Bro Morgannwg Health Board	Short	19		General	Apologies for repetition but the absence of any mention of PBS is noticeable by its' absence on this page, despite it being highlighted by expert witness testimony and other research cited in the evidence section	Thank you for your comment. Interventions and approaches to treat, manage or prevent behaviour that challenges is in scope for the clinical guideline that accompanies this service guideline and we have provided a reference and hyperlink as follows, (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, for people who wish to know more. We agree it would be helpful to have a definition of Positive Behaviour Support as we also reference the Positive behaviour support competence framework.

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						in recommendations 1.9.2 and 1.9.3 and have added a definition used in the clinical guideline in the terms used section.
Abertawe Bro Morgannwg Health Board	short	20		general	There is nothing to disagree with regarding the recommendations on housing – but the point should be made that there is an evidence base that small scale community based 'ordinary' housing provides the best environment for the achievement of a range of outcomes— e.g. see Felce, D. (1993), ''Ordinary housing: a necessary context for meeting service philosophy and providing an effective therapeutic environment'', in Jones, R. and Earys, C. (Eds), Challenging Behaviour and Intellectual Disability: A Psychological Perspective, BILD Publications, England, pp. 121-47. People (with LD & BTC) are often dependent on support to live in any form of housing. However, there is little in this section concerning the nature of that support. In the 'supported living' funding arrangements there is often an appropriate separation between landlord and support provider functions. Highlighting the need to focus on 'support' in addition to 'housing'. Emphasising that the support provided must conform to this guidance would be helpful. Support providers should be commissioned on a clear contractual basis to provide quality care based on current best practice a reference to the PBS academy standards for services would be relevant here http://pbsacademy.org.uk/wp-content/uploads/2017/10/PBS-Standards-for-services-Oct-2017.pdf	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life but that it was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, the Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home like is more like an ordinary home for most people. The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation. Thank you for including references- we did not include the Felce 1993 study you mentioned as this was published before the policy context date inclusion criteria of of 2001,(Valuing People) and was an overview of research rather than empirical research. We did however, include more up to date studies by the same author: Felce D J, Perry J, Romeo R, Robertson J, Meek A, Emerson E, and Knapp M. (2008). Outcomes and costs of community living: semi-independent living and fully staffed group homes. American Journal on Mental Retardation, 113(2), pp.87-101. Felce D. (2016). Community living for adults with intellectual disabilities: unravelling the cost effectiveness discourse. Journal of Policy and Practice in Intellectual Disabilities, , pp.Advance online publication. doi:10.1111/jppi.12180. Perry J, Firth C, Puppa M, Wilson Rick, and Felce David. (2012). Targeted Support and Telecare in Staffed Housing for People with Intellectual Disabilities: Impact on Staffing Levels and Objective Lifestyle Indicators. Journal of Applied Research in Intellectual Disabilities, 25, pp.60-70. Robertson Janet, Emerson Eric, Pinkney Lisa, Caesar Emma, Felce David, Meek Andrea, Carr Deborah, Lowe Kathy, Knapp Martin, and Hallam Angela. (2004). Quality and Costs of Community-Based Residential Supports for People with Mental Retardation and Challenging Behavior. American Journal on Mental Retardation, 109, pp.332-344. Perry J, Allen D G, Pimm C, Meek A, Lowe K, Groves S, Cohen D, and Felce D. (2013). Adults with intellectual disabilities and challenging behaviour: the costs and outcomes of in- and out-of-area placements. Journal of Intellectual Disability Research, 57, pp.139-152. Perry J, Felce D, Allen D, and Meek A. (2011). Resettlement Outcomes for People with Severe Challenging Behaviour Moving from Institutional to Community Living. Journal of Applied Research in Intellectual Disabilities, 24(1), pp.1-17.
Abertawe Bro Morgannwg Health Board	short	27	17/18	1.9.1	The use of the term Positive Behavioural Support would bring additional clarity in the first bullet point or elsewhere Practice leadership is increasingly recognised as a key feature of quality services, particularly related to the implementation of good practice. However, it is not mentioned at all in this section, despite there being a managerial and supervisory level of the PBS competence framework that reflects this and directly refers to practice leadership. This section should be considerably expanded through collaboration with key organisations and professional bodies See for example http://pbsacademy.org.uk/standards-for-training/	Thank you for your comment. The Guideline Committee agree that it is important for staff to have the necessary skills and competencies to work with people with a learning disability and behaviour that challenges, in line with the general principles of care section of (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have referenced the recommendations relating to 'staff training, supervision and support'. Recommendations 1.9.2 and 1.9.3 reference and link to the Positive behaviour support competence framework for direct and supervisory level contact, which includes managerial and supervisory and higher level competencies. After careful consideration, we think that this is adequately covered in the references and links in these recommendations. NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the Positive behaviour support competence framework is provided for people to find more detailed information.
Abertawe Bro Morgannwg Health Board	short	28	general	Terms used	Under 'terms used….'Include an accurate contemporary description of PBS	Thank you for your comment. We have added a definition of Positive Behaviour Support to the 'Terms used' section as you suggest.

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Abertawe Bro Morgannwg Health Board	Short	30	general	Putting this guidance into practice	Practice leadership would be of particular relevance here as would the existing resources available from some of the organisations mentioned earlier such as Challenging Behaviour Foundation http://www.challengingbehaviour.org.uk/ PBS academy http://pbsacademy.org.uk/ ,British Institute of Learning Disabilities, http://www.bild.org.uk/our-services/positive-behaviour-support/capbs/ Greater collaboration with these organisations would help ensure successful implementation	Thank you for your comment. The Guideline Committee agree that it is important for staff to have the necessary skills and competencies to work with people with a learning disability and behaviour that challenges. In line with the general principles of the care section of NICE's guideline on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) . We have referenced the recommendations relating to 'staff training, supervision and support'. Recommendations 1.9.2 and 1.9.3 reference and link to the Positive behaviour support competence framework for direct and supervisory level contact includes competencies which refer to managerial, supervisory and higher level competencies.
Abertawe Bro Morgannwg Health Board	full	31	general	Research Recommendations	Research Recommendations These are broadly relevant and appropriate	Thank you for your comment and support for this research recommendation.
Abertawe Bro Morgannwg Health Board	short	7	12	Aims and principles	These aims could be improved by addition of a statement such as 'Help people to have a good quality of life'	Thank you for your comment. We have revised this text in the aims and principles to say 'help people to have a good quality of life'.
Abertawe Bro Morgannwg Health Board	short	8	general	1.1.1	All of this section is appropriate, relevant and reflects good practice. However, there are barriers to its implementation and additional further guidance on best practice in many areas is required. For example; The desired move towards pooled budgets requires clear policy leadership from national and devolved governments to be achieved. The current eligibility criteria, interpretation and practice regarding Continuing Health Care funding for this population in Wales causes considerable dispute and delay at present, greatly impeding integrated commissioning. More detailed, effective and practice based population assessment and planning models are needed.	Thank you for your comment and support for these recommendations. While recommendations for national and devolved governments and specific funding mechanisms are out of scope for this guideline, the recommendations are based on the best available evidence and supports the use of pooling budgets and other resources to meet the needs of this population. We note that the aims of the Transforming Care programme states that "NHS England will support Clinical Commissioning Groups (CCGs) to co-commission specialised NHS services with NHS England, NHS England, the LGA and ADASS will continue to promote joint working and pooled budgets between CCGs and local authorities' (Transforming Care Next Steps 2015). We hope that these combined efforts will encourage implementation of best practice recommendations for integrating health and social care by including pooling budgets and resources.
Abertawe Bro Morgannwg Health Board	Full	General		general	The guidance is generally very appropriate and comprehensive and if implemented could considerably improve the quality of life of people with learning disabilities who have behaviours that challenge. The recommendations outline an appropriate range of service to meet needs and will help guide local service structure and future provisions helping people to remain in and be part of their local communities. There is a good fit with legislation and Policy initiatives in the UK e.g. such as The Social Services and well-being (Wales) Act. They are based on developing good practice and research evidence and the references to Positive Behavioural Support (PBS) are particularly welcomed. The recommendations concerning future research appropriately highlight the need to utilise robust methodologies to further explore the evidence base. However, this guidance would be considerably improved by additional direct reference to Positive Behavioural Support (PBS), such as defining the term in the glossary and use of the term within the recommendations, because many of the recommendations reflect the PBS framework (see for example Gore et al (2013) Definition and Scope for Positive Behaviour Support. International Journal of Positive Behavioural Support 3(2), 14-23, Hastings et al., (2013) 'A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities', International Journal of Positive Behavioural Support, 3(2), 5–13.) There is an increased interest, understanding and development of good practice that falls with the PBS framework, throughout the UK and	Thank you for your comment and support for this guideline. We have followed your suggestion and added a definition for positive behaviour support to the list of terms used in this guideline. After careful consideration, we think that this is adequately covered in the references and links in these recommendations. Recommendations 1.9.2 and 1.9.3 reference and link to the Positive Behaviour Support competence framework for direct and supervisory level contact, which includes managerial and supervisory and higher level competencies. A hyperlink to the Positive Behaviour Support competence framework is provided for people to find more detailed information The Guideline Committee also gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.

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					internationally. (See for example work by the Challenging Behaviour Foundation http://www.challengingbehaviour.org.uk/ PBS academy http://pbsacademy.org.uk/ ,British Institute of Learning Disabilities, http://www.bild.org.uk/our-services/positive-behaviour-support/capbs/ Mencap etc.) Direct use of the term PBS within the recommendations would greatly assist in the implementation of the guidance by building on this developing good practice. This is shown to some degree in the research studies and expert witness testimonies included in the evidence section. However, emerging good practice in PBS is under-represented in the guidance as it currently stands. The inclusion of examples of good PBS practice in the final version would greatly assist with implementation and the aim of improve the quality of life of people, their families and carers. It is often the family members and staff in closest contact with the person with LD who suffer the greatest stress and need to have the clearest understanding of the terminology associated with good practice. Indeed families and advocates need to have a vocabulary to articulate what they want from service providers and commissioner and for there to be a shared understanding of what this entails. The increased use of the term Positive Behavioural Support would considerably assist this. The need for additional financial resources and major changes in how current financial resources are utilised to meet the current and future needs of this population is very apparent to the key stakeholders. Consideration of the additional financial and other resource aspects will be essential in translating the guidance into good practice.	
ABA Access4All	Short	14		1.2.16	The emphasis on the use of Personal Budgets is good to see, giving parents more flexibility when the local offer is not up to scratch. We parents don't have time to wait around while provision is improved, so giving us the buying power to get the right specialist help in the meantime makes sense. Economic as well as emotional sense, given the costs of secure hospital placements when crisis points occur.	Thank you for your comment and support for this guideline, which we hope will contribute to making the management and use of personal budgets more accessible for all.
ABA Access4All	Short	15		1.3.1	Absolute hats off to you for including the vital professionals in the behaviour analysis field in this list. At last! It is unfair on all concerned to expect SALTS or OTs to deal with really serious challenging behaviour, as has been happening out here, when there's an actual profession that knows what it is doing. Without ABA, my beloved son would now be beating me up. No doubt at all.	Thank you for your comment. Following stakeholder feedback, and further consideration by the Guideline Committee, we have removed the term Behaviour analyst from recommendations when used as a profession title. We have kept the term 'behaviour support' to be a generic term for behavioural interventions that are in line with the evidence-based interventions in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
ABA Access4All	Short	19		1.4.7	More references to specialist behaviour support, great to see.	Thank you for your comment and your support for the guideline.
ABA Access4All	Short	22		1.6.1	Very pleased to see CAMHS mentioned, as this seems a good place for behavioural support specialists to be placed. Previously my and other mums' experience suggests many CAMHS services only really offer meds like Ritalin or risperidone for challenging behaviour, not FBAs and trying behavioural methods first (as NG11 suggests should be the case).	Thank you for your comment and support for this recommendation.
ABA Access4All	Short	27		1.9.2	Good reference to the very thorough PBS Competency Framework, great to see	Thank you for your comment.
ABA Access4All	Short	4		Backgrou nd	I think it quite likely that the number of children with LD is an under-estimate, as you do not cover autistic children. In general in the UK, autism tends to get used as an "umbrella" diagnosis and the degree or presence of Learning Disabilities on top is omitted. My own son only has a diagnosis of SLD on top of the autism because we requested a full cognitive analysis via a personal	Thank you for your comment. The scope of the guideline includes adults and children and young people with autism and who also have a learning disability. After further consideration, the Guideline Committee agreed that this needed greater clarification and have revised the background section to make this clearer.

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					contact at the Maudsley. Without it, his diagnosis would likely just have been "autism". Most of the parents on my campaign have not really been told whether their child has autism and a Learning Disability, or just autism. It's a big gap and has huge implications for provision, as autism with and without LD are really two different things. Just a comment really, not sure what is to be done. The autism world is full of fluff and eclecticism, and tends to reject therapies such as ABA even when challenging behaviour is severe. We are therefore letting down whole generations of kids with autism and (an undiagnosed) LD, who might have received better, earlier help and avoided going into 'residential' in their teens when their parents could no longer cope with challenging behaviours (often, aggression or SIB).	
ABA Access4All	Short	7		Aims	I really applaud the emphasis on prevention rather than just crisis management after the fact. Teaching my boy, via ABA, not to express his emotions with his fists (on himself or others) has been very timely as he is now well into the teenage years and is 6ft and 12 stone. Sorting out challenging behaviour in the teens is so much harder. Putting in place good habits early on makes sense for all concerned. I also really like the emphasis on keeping our CYP in their own homes, with their own families – or, failing that, at least close to home in their own communities rather than getting sent hundreds of miles away to ATUs that really often provided no A or T anyway. My boy is my child, it would break my heart and his to send him away from his own home and family, just for the want of the right kind of behavioural and preventative support. Thank you for this guideline.	Thank you for your comment. The Guideline Committee agree that it is important to emphasise prevention and early intervention before admission to inpatient hospital. The order of the recommendations places exploring all other options to inpatient first. The final recommendation 1.8.8. states that interventions should follow those in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for evidence-based interventions that specifically address their needs and the reason for their admission and who should deliver them. We have revised and strengthened other recommendations in placing a greater emphasis on supporting families and on prevention and early intervention.
Action on Hearing Loss	Short	1.1	19	Achieving change	We support the idea of commissioners ensuring funding mechanisms for providers support flexible and creative community based responses, for example, a contingency fund that providers can draw on quickly if there was a crisis. However, we feel this could be challenging in practice and would need detailed guidance how it could work and how providers could access it. In reality, providers may not be supported with this. We feel that commissioners often do not recognise that a crisis is occurring and the thresholds in care settings are too high – this causes risk of harm to staff and people supported. Any emergency funding should also consider other needs such as culturally appropriate provision for people who are deaf etc.	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. This is on the basis that the guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation. After further consideration, the Guideline Committee considered that greater investment in areas of supporting families, prevention and early intervention should make savings elsewhere in the system, including high cost crisis response.
Action on Hearing Loss	Short	11	14	1.2.3	We welcome the guidance that providers should match skills of staff to the characteristics of the person with the learning disability. The next sentence 'do this as soon as care planning begins' is harder to meet. Person centred support planning is an ongoing process where the staff work in detail with the person and their families/ loved ones and other health professionals to identify what is important to and for the person. Providers can only match staff effectively if this detailed work has taken place.	Thank you for your comment. We agree that staff involved in the care and support planning should get to know the person and their family to find out what they want, not just about services. This is reflected in recommendation 1.2.14 which involves: adopting a 'whole life' approach that covers what they want to achieve in both the short and long-term and supports: • smooth transitions • takes a positive approach to managing risk • sets out what to do to prevent or respond to a crisis. If implemented as intended, the Guideline Committee feel that matching skills to the person should happen as soon as care planning begins.
Action on Hearing Loss	Short	12	10	1.2.7	We welcome the inclusion of people having access to specialists in communication when needed, however feel that this statement needs to be strengthened by referring to the Accessible Information Standards directly and particularly that professionals and relevant staff should proactively prompt individuals to identify that they have communication needs, and support them to describe the type of alternative format and/ or support that they need.	Thank you for your comment. We have revised this recommendation to include reference to the Accessible Information Standard.
Action on Hearing Loss	Short	General	General		Question1: We agree with the guidelines, and the person centred nature of the interventions and requirements for personal budgets is welcomed. We are	Thank you for your comment, and for your support for the guideline. We hope that the guideline will support changes in practice. The recommendations on forensic services have been amended following

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					concerned that not a lot will occur in practice. The multi-agency work is also welcomed but may be more challenging where forensic services need to be involved. The forensic service has to be appropriate for the needs of the person, for example, National Deaf Services – we find real barriers to people getting appropriate referrals.	stakeholder comments to make them more broadly applicable. The recommendations are now clearer that these can be provided as stand-alone teams, or as a specialism within an existing team, for example, a community learning disability team.
Action on Hearing Loss	Short	General	General		Question 2: We fear this guidance will not lead to cost implications, but it should do if commissioners implement properly. At present we feel commissioners are reluctant to take action when someone lives in a care home by agreeing to top up funding for extra staffing etc. People's needs and therefore support and staffing requirements can change and particularly when reaching crisis points commissioning needs to be flexible and support requests for increased funding. It is not clear how these guidelines will improve this situation faced by providers. We are concerned the guidelines are quite general and there is a chance that local authorities will claim they are already doing these things when providers feel differently.	Thank you for your comment. Recommendation 1.1.5 states that the lead commissioner should ensure that funding mechanisms for service providers support creative and flexible community-based responses, for example, a 'contingency fund' that service providers can draw on quickly if there is a crisis. The Guideline Committee have worked to make the recommendations as specific as possible, whilst allowing for flexibility in local delivery.
Action on Hearing Loss	Short	General	General		Question 3: We feel along with this guidance there should be promotion of good practice, showing the impact of initiatives and also being specific about the extra provision this will provide.	Thank you for your comment. This guideline aims to support good practice. NICE also routinely produce baseline assessment and resource impact tools. To encourage the development of other practical support tools, we run an endorsement scheme aimed at encouraging our partners to develop these in alignment with NICE recommendations. Eligible tools are assessed and if successful, will be endorsed by NICE and featured on the NICE website alongside the relevant guideline.
Action on Hearing Loss	Short	General	General	general	Overall we feel that the guidelines are positive and running through the guidelines are all the key values and approaches which are embedded in our work and very familiar to us, such as involving people supported in development of plans for the future, person centred working and positive behaviour support. We fully support the guidance around a shared approach to commissioning. We agree ☐ That a lead commissioner should be appointed with in depth experience and knowledge of learning disability and behaviour that challenges. ☐ That there should pooling of budgets/ other resources and a contingency fund available to providers when needed ☐ That they should actively predict need and plan for this ☐ That risk should be shared ☐ That commissioning should make use of experts by experience ☐ That services need to include crisis response and intervention to prevent people being moved out of their home or community ☐ That people should have access to a named worker to coordinate their support	Thank you for your comment and support for this guideline.
Affinity Trust	Full	General		general	The guidelines are comprehensive and thankfully ties in with the previous guideline on assessment and interventions. It does read a little NHS/health driven in places. With limited information on measuring outcomes successfully It would be nice to see provision for some person-centred measures included i.e. measures that people develop themselves in collaboration with their network. Good to see lots of referencing to PBS Competence Framework, particularly in relation to staff skills.	Thank you for your comment and support for this guideline. We agree that outcome measures should be person-centred and have revised recommendation 1.1.10 to include measures that includes evidence from quality reviews and spot checking involving experts by experience and quality checks by user-led organisations and that this information should be used to continuously improve services (see recommendation 1.1.13).

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Association for Dance Movement Psychotherapy				general	If the Arts Psychotherapies continue to be left out of documents such as this NICE guidance then commissioners will not understand until it is too late how much the Arts Psychotherapies have to offer in terms of the "Transforming Care Agenda" and services will be redesigned without the Arts Psychotherapies being included. This will limit the services available for some of the most vulnerable children and adults who have limited or no verbally communication and rely on support staff and families who know them well to understand their needs. Arts Psychotherapies offer an alternative non-verbal approach for psychological and emotional expressions, including working with children and adults who have experienced trauma, loss or bereavement.	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Association for Dance Movement Psychotherapy				general	Arts Psychotherapies commissioned proactively in the community would reduce the impact of costly in-patient admissions in both financial and emotional distressed caused to the child, adult or their family when services are limited to reactive commissioning when in-patient services become the only option left available for behaviour described as challenging.	Thank you for your comment. We have revised the recommendations that list the specialist services that should be made available to providing support. Individual interventions are not in scope for this service guideline but we have referenced to the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) where appropriate.
Association for Dance Movement Psychotherapy				general	Arts Psychotherapies are an alternative to restrictive practice and the use of medication. The Association for Dance Movement Psychotherapy is a member of the Arts Psychotherapies represented on the Learning Disability Senate and have signed up to the STOMP campaign. Arts psychotherapies can offer support in the development of Positive Behaviour Support plans including understanding the emotional stages of distress; enabling the child or adult to recognise, communicate their needs, and support the development of person centred strategies to enable them to live full and rewarding lives in the community, close to their family and friends.	Thank you for your comment. We have revised the recommendations that list the specialist services that should be made available to providing support. Individual interventions are not in scope for this service guideline but we have referenced to the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) where appropriate.
Association for Dance Movement Psychotherapy	Short	13	22-28	1.2.14	We would like you to consider naming the Arts Psychotherapies (Art, Drama, Music and Dance Movement Psychotherapy) in addition to "Psychology" as a useful intervention for children and adults with a learning disability and behaviour described as challenging. Arts Psychotherapies have been working with this client population for many years as part of multi-disciplinary teams and use the creative arts as a non-verbal approach to communication and psychotherapy. Arts Psychotherapies can be in addition to Psychology and incorporated into a Positive Behaviour Support plan in the following ways. Arts Psychotherapies offer the opportunity for children and adults with a learning disability to express themselves non-verbally and explore their emotional needs in a group or 1;1 individual weekly sessions. Dance Movement Psychotherapy has developed since the 1960's and is currently establishing an evidence based as an intervention. Please see a list of published research references below offer more information. Related Publications	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically

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					Hartshorn K. et al. (2001) Creative movement therapy benefits children with autism. Early Child Development and Care. Hildebrandt M. K., Koch S. C., Fuchs T. (2016) We dance and find each other: Effects of dance-movement therapy on negative symptoms in autism spectrum disorder. Behavioral Sciences. 6(4) Koch S. C. et al. (2015) Fixing the mirrors: A feasibility study of the effects of dance movement therapy on young adults with autism spectrum disorder. Autism. 19(3) See C. (2012) The use of music and movement therapy to modify behaviour of children with autism. Pertanika Journal of Social Sciences and Humanities. 20(4), Srinivasan S. M., Bhat A. N. (2013) A review of 'music and movement' therapies for children with autism: embodied interventions for multisystem development. Frontiers in Integrative Neuroscience. 7(22), Srinivasan S. M. et al. (2015) The effects of rhythm and robotic interventions on the imitation, praxis, interpersonal synchrony, and motor performance of children with autism spectrum disorder (ASD): A pilot randomized controlled trial. Autism Research and Treatment.	
Association for Dance Movement Psychotherapy	short	15		1.3.1	As above, we would like the Arts Psychotherapies to be named in this section in addition to Psychology, Speech & Language Therapy and Occupational Therapy. Dance Movement Psychotherapy can be a useful intervention to support family carers and children to communicate through movement as described by Devereaux below. Moving into relationships: Dance/movement therapy with children with autism. Citation: Play-based interventions for children and adolescents with autism spectrum disorders., Jan 2012,(2012),p.333-701(2012) Author(s): Devereaux, Christina Abstract: Discusses the use of dance/movement therapy (DMT) and how the therapeutic process can serve both as a bridge for contact and a vehicle for expressive communication for individuals with autism (ADTA, 2011). Particular emphasis is placed on DMT's unique facility for understanding, reflecting, and expanding non-verbal expression and how this can help those with autism to improve socialization and communication and to build body awareness and can enhance relational engagement. Supportive literature addressing concepts in neuroscience, social engagement theories, attachment, and infant research complements the discussion. Case illustrations are highlighted to provide concrete examples of these theoretical concepts. (PsycINFO Database Record(c) 2016APA, all rights reserved)(chapter) Source: PsycInfo	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. A separate NICE guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Association for Dance Movement Psychotherapy	short	17		1.4.3	[note SH only quote 1.4.2 – but looks to relate to 1.4.3 as well] As above we would like you to consider naming the Arts Psychotherapies in this section as many Arts Psychotherapists are working to support children and adults to be able to be supported in the community and prevent the need for inpatient services.	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline which accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered intervention. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that

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					Arts Psychotherapists are also working within In-patients' services to support the development of children and adults to be able to return to their local communities. As an example, Jeong Y J and Hong, S C (2005) Dance Movement Therapy Improves Emotional Responses and Modulates Neurohormones in Adolescents with Mild Depression, International Journal of Neuroscience, 115:1711–1720 Joeng and Hong (2005) completed an RCT that assessed changes in psychological health and neurohormones of adolescents with mild depression who took part in the 12 week dance movement therapy group. Forty middle school seniors (mean age: 16 years old) volunteered to participate in this study and were randomly assigned into either a dance movement group (n = 20) or a control group (n = 20). The study reported that scored relating to psychological distress from the 20 adolescents attending dance movement therapy sessions significantly decreased, plasma serotonin concentration increased and dopamine concentration decreased. It is suggested that dance movement therapy may be effective in mild depression through stabilising the sympathetic nervous system. Edwards, J. 2015, "Exploring sensory sensitivities and relationships during group dance movement psychotherapy for adults with autism", Body, Movement and Dance in Psychotherapy, vol. 10, no. 1, pp. 5-20. Unkovich, G., Butté, C., & Butler, J. (2017) Dance Movement Psychotherapy with people with Learning Disabilities. Routledge. This book provides an overview of dance movement psychotherapy for young people and adults with learning disabilities. Contributors from a variety of backgrounds examine their work with clients from across the disabilities spectrum, ranging from mild to complex needs. The book chapters present theory and practice relating to the client group and subsequent therapy processes. This comprises psychotherapeutic interventions, dance movement interventions, theoretical constructs, case study material, practitioner care, and practitioner learning and development related to individual and group therapy work. The logistics of a Dance Movement Psychotherapy intervention, the intervention itself and the ripples of influence into the clients' wider socio-cultural context are discussed. This stance speaks to current research and practice discourse in health and social care. Neuroscientific research, dance movement psychotherapy and relationships. Within dance movement psychotherapy, the following empirical studies offer evidence on the impact of kinaesthetic empathy on the brain:	should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.

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					Rova, M. (2012-2015) Embodying Kinaesthetic Empathy as an Intersubjective Phenomenon and Clinical Intervention: a practice-based interdisciplinary study combining Dance Movement Psychotherapy, Phenomenology and Cognitive Neuroscience. London: University of Roehampton (PhD research) Fischman, D. (2009) Therapeutic Relationships and Kinesthetic Empathy in Chaiklin, S. & Wengrower, H. (Eds.). The Art and Science of Dance/Movement Therapy: Life is Dance. New York/London: Routledge McGarry, M. L. & Russo, F.A. (2011) Mirroring in dance/movement therapy: Potential mechanisms behind empathy enhancement. The Arts in Psychotherapy, 38, 178-184 Beausoleil, E. & LeBaron, M. (2013), "What Moves Us: Dance and Neuroscience Implications for Conflict Approaches: What Moves Us", Conflict Resolution Quarterly,vol. 31, no. 2, pp. 133-158. Pierce, L. 2014, "The integrative power of dance/movement therapy: Implications for the treatment of dissociation and developmental trauma", The Arts in Psychotherapy, vol. 41, no. 1, pp. 7-15. Cochrane Systematic Review: Meekums B, Karkou V, Nelson EA. Dance movement therapy for depression. Cochrane Database of Systematic Reviews 2015, Issue 2. Art. No.: CD009895. DOI:10.1002/14651858.CD009895.pub2. The review recommended the need for further research. Meta-analyses: Koch S, Kunz T, Lykou S and Cruz R (2014) Effects of dance movement therapy and dance on health-related psychological outcomes: A meta-analysis, The Arts in Psychotherapy, 41, 46-64. This meta-analysis looked at the effectiveness of dance movement therapy and dance from 23 primary trials (N = 1078) including studies with children and adolescents on variables of quality of life, body image, well-being, and clinical outcomes, with sub-analysis of depression, anxiety, and interpersonal competence. Results suggest that these interventions are effective for increasing quality of life and decreasing clinical symptoms such as depression and anxiety. Positive effects were also found on the increase of subjective well-being, positive mood, affect, and body image. Effects for interpersonal competence were	

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					encouraging, but due to the heterogeneity of the data remained Inconclusive. Systematic Literature Reviews: Randomised controlled trials are also included in narrative systematic reviews in the field, some of which refer to children and adolescents with attachment issues: Kiepe, M.-S., Stöckigt, B., & Keil, T. (2012). Effects of dance therapy and ballroom dances on physical and mental illnesses: A systematic review. The Arts in Psychotherapy, 39(5), 404–411.	
Association for Real Change	Short	11		1.2	Person Centred Care and support is vital to empowering people with learning disabilities and or autism and those who display behaviours of concern. We wholeheartedly believe that providers should be adhering to the principles of Active Support (see the findings of the Jim Mansell's reports in to the benefits of this.) Active Support is a way of working and promotes culture that should be owned by providers and encourages managers and staff to look at every opportunity to engage people in their own lives. It moves away from the 'hotel model' where workers tend to do everything for the person, leaving them disengaged, to participation in everyday activities, where workers work with the person. Active Support is also a pre-cursor to Positive Behaviour Support.	Thank you for your comment and your support for the person-centred approach that underpins the guideline. Specific interventions are the focus of the clinical guideline and we have referred to this where appropriate. This guideline seeks to complement rather than replicate the existing guideline (NG11) which focuses on prevention, management and treatment of challenging behaviour. We did not find robust research evidence supporting the use of Active support in community settings or as a service, the focus of this guideline.
Association for Real Change	Short	12	22-24	1.2.9	We agree with this recommendation. It is so important to have a single point of contact for families and it also means greater effective communication and ability to co-ordinate requirements all the way through someone's 'journey' without vital information being lost. In addition to this, our members have advised that they have seen huge benefits of working with an assigned/named worker, as they have knowledge of the person rather than having to go through past history over and over again.	Thank you for your comment and your support for the recommendation.
Association for Real Change	Short	12	25-29	1.2.10	We agree with this guideline. It is vital that people who access services have the option to access advocacy services, which unfortunately, even though it is laid out in the Care Act, are seriously lacking in availability. Of course the input of family and providers is important but, seeking the supported persons own views on their own life is critical. Major life choices may not always be thought of as often the concern for families and providers is on risk aversion, rather than sexuality, relationships etc – key parts of citizenship and human rights.	Thank you for your comment and support for the guideline. The Guideline Committee agree that access to advocacy services is important.
Association for Real Change	Short	13	12-28	1.2.12	Our members agree that their input is vital to offer a more well rounded service to the individual, as providers have sound knowledge of the person and personal experience of working with them.	Thank you for your comment and support for this recommendation.
Association for Real Change	Short	13-14	29-8	1.2.15	Our members see this as vital to ensure there is an opportunity to look at the care and support of individuals on a more flexible basis. The Community teams need to take the lead in this as to ensure effective co-ordination.	Thank you for your comment and your support for the recommendation.
Association for Real Change	Short	14	13-29	1.2.17	Personal budgets are very helpful for individuals as it allows greater opportunities to offer/allow access to truly person centred support. One key area to consider is the practicalities of the application process itself that can be over burdensome for people with learning disabilities and autism to work through. It would be very beneficial to explore HOW people could be supported to set up and maintain their own budget and services.	Thank you for your comment. We have included reference to the accessible information standard in recommendation 1.2.6, which applies to all staff working with people with a learning disability and behaviour that challenges and their families. We did not find research evidence specifically on effective mechanisms and methods of helping people use their budgets. The Guideline Committee agreed that the level of detail in this recommendation would suffice on the basis that the guideline is relevant to an

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						extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation.
Association for Real Change		15	14-24	1.3.3	It would be useful if there was a provider directory of sorts to ensure individuals and their family can exercise greater choice and control.	Thank you for your comment. In recommendation 1.3.3 we suggest that information about support and services be made in the form of a 'welcome pack' and the information provided should relate to the recommendations in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), that relate to the support and interventions for family members or carers. We have provided a hyperlink to this section for people who wish to know more. We will also pass this information to our local practice collection team. More information on local practice can be found here (https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies)
Association for Real Change		18	6-14	1.4.4	Our members agree this is the correct approach as it promotes consistency and better joined-up working.	Thank you for your comment and your support for the recommendation.
Association for Real Change		19	10-24	1.4.9	These recommendations for intensive behaviour support are definitely required and would be extremely valuable. In particular, the out of hour's advice line would be extremely helpful to families in the community. One provider member quoted: "In our experience the major issue with continuing to support someone in their current placement when in crisis is about managing the impact and safety on others in the current environment (other service users, neighbours, family members or people in the community), rather than being able to actually manage the person's behaviour. In these situations having somewhere else to go temporarily, in the form of suitable respite placements available (i.e. sturdy, non-shared services, with skilled staff) may be the most important thing needed to avoid placement breakdown or hospitalisation."	Thank you for your comment and your support for the recommendations.
Association for Real Change	Short	20		General	We know of some providers who have changed their development model of new services to a supported living model whilst still offering the same level of support that would be needed if the individual lived in a residential service. Our members have cited that they have found the model very effective. It has helped support the wellbeing of service users and has reduced behaviours that challenge, which of course then minimises the impact of this on others. This also enables a cost effective way to have 24 hour support staff who are shared and available at all times on site We believe there is still a place for residential services too if it is the right environment for the individual who is living there. We agree that it is more appropriate for people to live in their own home or in shared accommodation with a small number of others. The most crucial part of this is ensuring that the environment is right for the individual and their preferences, like, requirements are fully considered. Potentially a formal way of addressing compatibility would be beneficial.	Thank you for your comment. The Guideline Committee agreed on the importance of accommodation as a determinant of health and wellbeing. While there was no strong evidence to support recommendation of one type of accommodation over another, or the maximum number of residents to maximise choice, control and wellbeing, the Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
Association for Real Change	Short	22	7	1.5.8	Language: should be changed to day opportunities	Thank you for your comment we have revised this recommendation (now recommendation 1.2.23) as you suggested.
Association for Real Change	Short	25	2-12	1.7.2	In regards to respite services, consideration must be given to the environment, number of other accessing the service etc as placing individuals with other who they do not know, who may display unknown behaviours, causes a huge amount of stress.	Thank you for your comment. After careful consideration, we think that this is adequately covered in recommendations 1.7.1 to 1.7.3 through reference to breaks that are 'tailored to the needs of the person and their family or carers'.
Association for Real Change	Short	26	3	1.8.4	As mentioned in a previous point, there is a duty to offer advocacy services under the Care Act also. Association for Real Change	Thank you for your comment. We have revised this recommendation to include providing information about people's rights, including access to independent advocacy and other possible options for

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						treatment, care and support. We have created a new recommendation to reflect this is a legal duty under the Mental Health Act 1983 (recommendation 1.2.8).
Association for Real Change	Short	8	14-18	1.1.3	We that there are benefits to pooling resources, however there could be issues to ensuring service provision remains local for people who access support and their families.	Thank you for your comment. The Guideline Committee agreed on the importance of ensuring people are enabled to stay in their home area, near their family and community. This is referenced in the 'Aims and principles' and more specifically in recommendations 1.2.23, 1.4.7, 1.4.10, 1.4.12-1.4.14, 1.5.2, 1.5.7, 1.6.4, 1.6.10, 1.8.5-1.8.7.
Association for Real Change	Short	8	19-21	1.1.4	Our members fully support this recommendation. Too often relevant support, for when needs fluctuate, isn't available on a flexible and responsive enough basis. Although providers and their staff are able to work on an individual basis with the people they support, the more holistic and joined up agencies are to support people in all aspects is crucial.	Thank you for your comment and support for this recommendation.
Association for Real Change	Short	8	27-29	1.1.5	Our members agree. It's important that commissioning groups and Local Authorities have a clear understanding and data set to ensure current and future needs are met.	Thank you for your comment and support for this recommendation.
Association for Real Change	Short	8	2-9	1.1.1	We agree with this approach completely. Specialist knowledge within a single lead commissioner would ensure that there is a consistent approach with clear leadership. And experience of this previously has provided beneficial for the people they support.	Thank you for your comment and your support for the recommendation.
Association of Cognitive Analytic Therapy: Learning Disability Stream	short	27		1.9	The Positive Behavioural Competency Framework, although excellent as far as it goes, is insufficient. This framework describes how staff should respond to challenges, but does not consider how to support stressed, traumatised or angry staff who are coping with intolerable and overwhelming feelings. Mansell (2011) pointed out, "staff carried out this abuse under the noses of the nurses supposed to be managing them…". This guidance needs to consider how a culture of positive support degrades into a culture of neglect and abuse. This occurs when there are extravagant claims made about the efficacy of PBS and management are conditionally supportive (i.e., only wanting to hear positive news) towards striving staff. These staff soon find that their attempts to deal with challenging behaviours are ineffective and experiencing being unsafe or in an uncontrolled environment, there is a loss of compassion. When staff fail to follow PBS principles because they have reacted in a way they know they should not, staff often aware of their failures then tend to panic or blame themselves or others which over a short period of time leads to a facade of care. (Consider Emerson's 2002 staff stress survey for one of many examples). The issue is that community staff, who receiving far less skilled supervision than most staff in institutions, need regular support from skilled community staff and where such skilled trained staff are in such short supply, (such as psychologists or behavioural specialists), much neglect and abuse carries on in the community.	Thank you for your comment. The Guideline Committee agree that supporting staff to do their job well is vital to the delivery of evidence-based interventions and approaches and have recommended in 1.9.5 that staff should have staff support as well as supervision. We have provided a reference to the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) , recommendation 1.1.7,which recommends that Health and social care provider organisations should ensure that all staff get personal and emotional support to: enable them to deliver interventions effectively for people with a learning disability and behaviour that challenges and feel able to seek help for difficulties arising from working with people with a learning disability and behaviour that challenges., as well as recognise and manage their own stress.
Association of Cognitive Analytic Therapy: Learning Disability Stream	short	8		Achieving change	We are concerned that the high number of vacancies for community support staff who will work in family homes means that the ideals described in the guidance are not fulfilled and people are brought into residential care or assessment and treatment facilities owing to a lack of community support staff. There is a problem with gender imbalance as many staff who are prepared to work with people who challenge are male. There is a huge problem regarding the cost savings for community learning disability teams as there are less staff in post who could take on such intensive and long term work (particularly loss of LD specialists nurses since 2010 and the move of speech therapists from communication to dysphagia resulting in a severe loss of communication skills), We are also concerned that many private providers either hide the extent of the problems they are facing when working with people with	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The Guideline Committee was also concerned about the financial context and budgetary constraints and hopes that the recommendations of this guideline will help advocate for the commissioning, or continued investment in, evidence-based services. The Committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.

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					challenging behaviour because they fear a loss of business, or they rely on NHS community teams to pick up the shortfall in their skills. The main problem with implementing these guidelines however, is the effects of the cuts in local authority funding which means that the money is not there to pay for community services, which are either reduced or closed. It means an ever widening gap between the ideals described in these guidelines and the reality.	
Association of Cognitive Analytic Therapy: Learning Disability Stream	short	General		general	Most areas do not have any community forensic learning disability teams or even any community forensic learning disability trained staff embedded within other services.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. We have revised the text to make clear there is some flexibility locally in how this can be achieved and the recommendation now reads: These could be provided as stand-alone teams, or as a forensic specialism within a generic existing team, for example a community learning disability team or learning disability specialism within a community forensic team or in liaison and diversion teams.
Association of Cognitive Analytic Therapy: Learning Disability Stream	short	general		general	The main issue here is how can this guidance be implemented?	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The Guideline Committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system. The committee hope that the recommendations of this guideline will help advocate for the commissioning, or continued investment in, evidence-based services.
Association of Directors of Adult Social Services	Short	10	19-22	1.1.10	It would be challenging to implement the monitoring arrangements to the standard proposed due to personalisation, the range of providers and capacity within existing commissioning teams Multi-agency work can be risky and would favour this remit falling into an existing structure	Thank you for your comment. It is envisaged that the multi-agency group would monitor quality using the measures outlined in recommendation 1.1.10. An existing structure or group could be used to fulfil this function if appropriate. The recommendation has been amended to make this clearer.
Association of Directors of Adult Social Services	Short	10	27-29	1.1.12	This seems to be creating an additional financial burden and an additional post which may not be necessary. Some areas already have Expert by Experience services. Additionally, in lines 19-22 on the same page there is already provision to create multi agency group to inform commissioning.	Thank you for your comment. The Committee considered it important to reference experts by experience explicitly to ensure they are included and considered at all stages We have amended the recommendation to say that "Commissioners should employ experts by experience or make use of existing expertise from experts by experience to inform decision-making and quality assurance of services". This provides more flexibility and would mean not having to employ new people but also ensures that the expertise comes from experts by experience rather than other people.
Association of Directors of Adult Social Services	Short	18	1	1.4.3	There are currently no learning disability forensic specialists in North West London. The community forensic services currently commissioned by NHS England exclude provision for patients with learning disabilities.	Thank you for your comment. These recommendations aim to improve practice in this area. The provision of specialist learning disability services is also supported by the Transforming Care service specifications. We have amended the recommendation to make clear that forensic specialism could be within a specific team, or sit within a broader community learning disability team.
Association of Directors of Adult Social Services	Short	19	17	1.4.9	Need to define what is meant by 'provide a response within an hour' Most community teams do not have capacity to respond to a crisis within 1 hour, particularly if this is out of hours. Having to provide a face-to-face response out of hours would be costly and would be challenging to arrange on a practical level due to the size of learning disability teams, potentially diluting the offer during normal working hours This recommendation will be challenging to implement as unclear which team would provide this, would need to ensure that safe advice is given and there are significant cost and resource implications.	Thank you for your comment. We have revised recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. The resource impact team did consider that the provision of intensive support during a crisis would likely incur costs to implement. They also said that implementing the guideline may also result in the following benefits and savings: lower rates of placement breakdown due to effective respire care and suitable housing. The unit cost per case of £31, 296 for a crisis resolution team for adults is taken from the unit costs of health and social care 2017. Lead commissioners will need to have 24/7 multi-disciplinary crisis support, and services should be developing in this way to meet the requirements of the Transforming

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						Care agenda. The Guideline Committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Association of Directors of Adult Social Services	Short	19	5-8	1.4.8	Needs a clearer definition of the wait time and how this is measured – is this from referral to treatment? !8 weeks seems a long time in comparison to other services eg. CAMHS	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We have removed reference to an 18 week target. We have revised recommendation 1.4.9 which now reads that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support while ensuring that waiting times for specialist behavioural support do not exceed NHS waiting time standards.
Association of Directors of Adult Social Services	Short	20	1-5	1.4.11	CCG's and local authorities are not responsible for commissioning forensic services. This is currently the responsibility of NHS England. If this area is to be added to the lead commissioner's portfolio, it makes the role even more unrealistic. Cost implications: If the responsibility for commissioning community forensic services is to fall to the LA and the CCGs, this will have significant cost implications. This cost should be met by NHS England	Thank you for your comment. The Guideline Committee's understanding is that forensic learning disability teams are commissioned locally, but there is an NHS England specification of what they should include. Whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Association of Directors of Adult Social Services	Short	23	10-13	1.6.5	This paragraph needs to reference tripartite funding, 38/52 week placements	Thank you for your comment. Specific funding arrangements are not within the scope of this guideline.
Association of Directors of Adult Social Services	Short	24	11-17	1.6.10	The review of EHCP plans is annual. It's the role of a tracking group to ensure all placements are appropriate, high quality, moving towards discharge and cost effective	Thank you for your comment. Education Health and Care Plans are not the focus of this recommendation. The text has been edited to clarify this.
Association of Directors of Adult Social Services	Short	7 20 21 10-11	7-10 21-27 3-11	1.5	The principle of enabling choice as to where a person wants to live is right where this is practical. However, this is not always realistic due to restrictions of the type of housing available in some areas and the financial implications. In London, there are a lot of tall town houses and fewer accessible properties that are in overcrowded neighbourhoods. Therefore, it is not always possible to consistently provide suitable and appropriate accommodation for people in their desired area so a degree of flexibility is needed. It will be challenging for Local Authorities (LA's) to find the type of housing described which is affordable, particularly in London. There also needs to be recognition that one size doesn't fit all and therefore NICE shouldn't be prescribing the number of people a person should live with. For some people with the most challenging needs who are unable to tolerate sharing space with others, it may be essential that they live alone. However, it is not affordable or realistic for LA's to offer every person with challenging behaviour the option of living alone. In London, there is a significant lack of affordable housing and the support costs for single person services are not sustainable. There are also existing larger properties offering more than 3 beds which work well which LAs may not want to decommission.	Thank you for your comment. The Guideline Committee agreed on the importance of accommodation as a determinant of health and wellbeing. While there was not strong evidence to support a recommendation of one type of housing over another, or the maximum number of residents to maximise choice, control and wellbeing, the Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.

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					Often, the types of houses made available to London areas for supported housing can be quite large and can house more than four people. The scheme would not be financially viable if rooms were left unused. There may be cost implications for the provision of self -contained flats as opposed to shared provisions. To overcome the challenges of these proposals we recommend the following are considered: A national incentive to private landlords and housing providers to offer affordable rents for people with learning disabilities or an increase in the housing benefit tenants get awarded. To fully meet the NICE guidelines, LAs and CCGs will need to receive adequate recurrent funding. It is not possible to continue doing more with less. There is a limit to what LAs can realistically do within their limited resources no matter how creative they continue to be or how many examples of good practice and toolkits they read.	
Association of Directors of Adult Social Services	Short	8	2-25	Achieving change	This recommendation will be challenging in practice. We are concerned that the Lead Commissioner role is not practical as it would have such a huge remit and an unmanageable workload. It would be a huge challenge to find a commissioner who has both the experience of commissioning health, social care and education and knowledge and understanding of the legal framework across both children's and adult's services. The proposed arrangement is out of kilter with the commissioning arrangements for most local authorities (LAs) without all age services and for areas where CCG and LA commissioning is not integrated; significant restructuring would be required with likely cost implications We would support senior oversight/leadership of these commissioning areas. There should be join up for health/social care and education but for young people and adults this is such a huge portfolio it would not be practical	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity. We have made a new recommendation 1.1.2 to clarify that the lead commissioner is a role that plans and oversees commissioning arrangements. We have revised recommendation 1.1.1 to say that the lead commissioner has overall oversight of the strategic commissioning of health, social care and education services.
Association of Directors of Adult Social Services	Short	9	27-31	1.1.7	It should never be a commissioner's decision to change a placement or put greater restrictions on a person. These decisions should be made by a qualified social worker or the relevant clinician and within the appropriate legal framework. This needs to be re-worded.	Thank you for your comment. The recommendation has been edited to include reference to working with other organisations, to reflect that the people involved will vary depending upon the specific situation and context.
Association of Directors of Adult Social Services	Short	General	General	General	Why is this guidance needed when Building the Right Support articulates the national service model?	Thank you for your comment. This guideline has been developed based on review of the best available evidence by a Committee of experts, and covers a wider remit in the services it recommends.
Association of Directors of Adult Social Services	Short	General	General	General	Why are the needs of people with forensic histories being bolted on to guidelines about challenging behaviour? The needs of this cohort are not compatible with the group traditionally considered to have challenging behaviour. There should be separate guidance for this cohort	Thank you for your comment. The research evidence suggests that there is considerable overlap in community learning disability teams' caseloads of people who have come into contact with the criminal Justice System because of behaviour that challenges and who experience poorer outcomes, and lack of access to specialised services.
Association of Directors of Adult	Short	General	General	G eneral	• What would help users overcome any challenges: • Examples of good practice • Resources • National Initiatives • Case Studies	Thank you for your comment. NICE guidance focuses on 'what works'. It is beyond the remit of NICE guidance to make recommendations about specific funding arrangements for care and support. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was

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Social Services					• Grants Clarity from NHS England about their future commissioning intentions in relation to community forensic services and the transfer of "dowry" funding to CCGs and LAs	important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Autism East Midlands	Short	10	19-22	1.1.10	How will the membership of the group be decided	Thank you for your comment. The composition of the group could be tailored to reflect local service provision arrangements, but should fulfil the function of monitoring the quality of services for people with learning disabilities and behaviour that challenges.
Autism East Midlands	Short	10	27-29	1.1.12	The inclusion of an expert by experience should not be tokenistic and include those who have alternative communication needs, including those who are non-verbal	Thank you for your comment. The Guideline Committee agreed strongly that the inclusion of experts by experience is meaningful and appropriately supported. Recommendations 1.2.6 and 1.2.7 reference the importance of accessing appropriate speech, language and communication expertise, as needed.
Autism East Midlands	Short	10	6-15	1.1.8	We thoroughly welcome the use of the evidence listed as we currently use them ourselves and would welcome published data in these areas	Thank you for your comment and support for this recommendation.
Autism East Midlands	Short	11	11-13	1.2.2	Who is the independent voice for families and carers to provide advocacy for them	Thank you for your comment. We have made a recommendation in the section on early intervention and support for families and carers that information on how to access advocacy should be provided to families in recommendation 1.3.3
Autism East Midlands	Short	12	13-20	1.2.8	This only provides for advocacy for those without capacity, advocacy should also be available for those who have capacity	Thank you for your comment. We have referred to the Care Act 2014 in this recommendation. The Care Act makes provision for providing independent advocacy for people with capacity.
Autism East Midlands	Short	12	22-29	1.2.9-1.2.10	This is what used to happen but cuts have meant this is no longer the case. We would welcome its reintroduction	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. We have recommended that the named practitioner is one of the people already working with the person – not a new member of staff. This means the resource impact will be less. We have also revised the recommendation to make it clearer about how local authorities, clinical commissioning groups and service providers need to work in partnership to coordinate care and support
Autism East Midlands	Short	15	2-9	1.3.1	These services are not routinely available so this may have resource implications	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and was aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. It considers the recommendations to be aspirational but achievable.
Autism East Midlands	Short	19	17	1.4.9	What is expected as a response needs to be defined: is this attendance or advice and guidance. This will require significant extra resources.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. The Guideline Committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Autism East Midlands	Short	19	2-4	1.4.7	Sufficiency of in locale services can be maintained but this requires commissioning of some element of over provision; or services will reach capacity and people will be referred out-of-area to where provision can be found	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.
Autism East Midlands	Short	20	3-18	1.4.11-1.4.15	For those with autism in secure settings who have capacity or no accompanying disability there is no clear pathway of help and support	Thank you for your comment. This guideline addresses the needs of children, young people and adults with a learning disability (or autism and a learning disability). Whilst there is a clinical guideline for this group (Autism spectrum disorder in adults: diagnosis and management. Clinical guideline (CG142) there is a gap, in relation to there not being a service specification for people with Autism and we will flag this to NICE.

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Autism East Midlands	Short	21	10-11	1.5.5	Is the number of people in housing predicated on a supported living only model as this is lower than previous guidelines such as residential care	Thank you for your comment. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. The Guideline Committee interpreted this evidence and evidence from the expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more like an ordinary home for most people. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
Autism East Midlands	Short	21	1-2	1.5.3	When people are in short term private housing there is no more tenancy protection than there is in residential care	Thank you for your comment. The Guideline Committee favoured accommodation which offered security of tenure and a split between supported service provision and accommodation. We have revised recommendation 1.5.3 to say that 'Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test'.
Autism East Midlands	Short	22	17-22	1.6.2	Where do people with autism fit as they do not necessarily fulfil a CAMHS pathway and families can be left in limbo	Thank you for your comment. The guideline covers children, young people and adults with a learning disability and autism.
Autism East Midlands	Short	23	15-22	1.6.6	Currently providers are not involved, in our case we have a high proportion of looked after children and access to valuable insights	Thank you for your comment. It was the view of the Guideline Committee that knowledge of services would be provided by the commissioner and practitioners involved in the discussion.
Autism East Midlands	Short	25	18-26	1.8.2	How will it be ensured that the expert by experience has experience relevant to the individual. If they do not it could become tokenistic	Thank you for your comment. Experts by experience in this recommendation are part of the Care and Treatment Review process and regulated by the Care Quality Commission. In future, the day-to-day activities of Experts by Experience will be managed by an external organisation(s) on behalf of the CQC who will ensure that the experts by experience meet the specifications of the CQC in terms of having lived experience of services relevant to the individual We have defined experts experience in the 'terms used' as people with lived experience of using services, including people with a learning disability themselves and their family members and carers. We hope that this definition will ensure that the involvement of experts by experience will be relevant to the individual who is considering an inpatient placement.
Autism East Midlands	Short	27	17-24	1.9.1	Who will be the arbiter of the types of qualifications that are relevant and at what level	Thank you for your comment. We have referenced the skills needed in staff training supervision and support in the clinical guidelines (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). National standards for staff development and formal qualifications are out of scope for this guideline.
Autism East Midlands	Short	30	14-23	1.1.1	A single all age LD commissioner is an active discussion point at the local TCP which spans more than one local authority with one local authority working towards combining services into an all age spectrum.	Thank you for your comment. It is useful to know that the recommendations align with current developments in practice.
Autism East Midlands	Short	30-31	24-1		Autism East Midlands has embraced the idea of training and involving parents and uses a hub methodology to engage with parents and foster carers across our geographic area of operations	Thank you for your comment. We will pass this information to our local practice collection team.
Autism East Midlands	Short	8	15-18	1.1.3	This feels like a reversal of the localisation agenda to a more regional base	Thank you for your comment. The Guideline Committee agreed on the importance of ensuring people are enabled to stay in their home area, near their family and community. This is referenced in the 'Aims and principles' and more specifically in recommendations 1.2.23, 1.4.7, 1.4.10, 1.4.12-1.4.14, 1.5.2, 1.5.7, 1.6.4, 1.6.10, 1.8.5-1.8.7.
Autism East Midlands	Short	8	3-9	1.1.1	What is the geographic area that a single commissioner would cover? How will they be supported and have the infrastructure to undertake this role?	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Autism East Midlands	Short	8 & 9	23-29 & 1-25	1.1.6	We completely support the clear lead and systems provided in the planning section to ensure services will be available where they are most needed	Thank you for your comment and support for this recommendation.
Autism East Midlands	Short	9	5-7	1.1.5	Families have clearly told us that Education, Health and Care Plans do not work, a view mirrored across the country, is this a reliable primary evidence source.	Thank you for your comment. The Education Health and Care Plans are listed as only one source of information in this recommendation which also emphasises the importance of using a range of other data.

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Avenues Group	Short	11	3-13	1.1.5	We believe that working closely with people's families is important as it allows us to get to know the person better, and therefore tailor their support to them. We also think it's important to communicate effectively with families such that they know what to do in response to a crisis, and to have contingency plans in place should this occur.	Thank you for your comment. The Guideline Committee agreed this is important and the recommendation has been edited to make explicit reference to the need to involve families, carers and advocates.
Avenues Group	Short	16	7-19	1.3.5	Having a named worker responsible for providing information to families so that they are well supported and informed would be highly beneficial for families and the people we support. At present families are often passed around and receive communication from various people, which leaves them feeling confused and frustrated. The implementation of this recommendation would help to avoid that.	Thank you for your comment and your support for the recommendation.
Avenues Group	Short	17	4	1.4.2	If children go into residential placements there should always be a plan in place for them moving to a less restrictive environment as soon as possible. At present, this isn't always the case and means the child ends up 'stuck'. Again, this would lead to savings for local authorities in the long-term.	Thank you for your comment. The Guideline Committee agree with this and it is represented in the children and young people services section (1.6) of the guideline.
Avenues Group	Short	19	10-24	1.4.9	We believe that having intense support available during a crisis would have a huge impact on keeping people out of hospital. We should have people who are able to respond during one hour, 24/7. At present, it is usually the police and A&E who respond during crises and this often ends up with people being admitted to secure units, which is not only extremely distressing but also costly. The support available could be a skilled support worker who would be able to reassure individuals and their families should they encounter a crisis out of hours. We believe the implementation of such support would be welcomed by families.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the Criminal Justice System or inpatient admission due to the lack of available specialist support in the community.
Avenues Group	Short	24	23-30	1.7.1	Having local respite services in place would lead to less people being admitted to hospital as a result of the fact there is not a building/service available for them to go to locally. Teams and services should be set up and in place so they are able to respond when needed and this would largely reduce the long-term costs of crises. This could be done across boroughs or local authority areas.	Thank you for your comment. The guideline emphasises the need to develop local capacity, and the importance of early intervention and prevention (see for example the 'Aims and Principles' section). We hope that the guideline will inform the commissioning and service planning process in this regard.
Avenues Group	Short	8	3-9	1.1.1	We believe having a single lead commissioner is extremely important and this would be a particularly positive step for learning disability services. It would mean that we could work with people across the life span and therefore put long-term plans in place as opposed to focussing on short-term outcomes for people, which is currently often the case. A single lead commissioner would know the area and the people living in it and this would lead to more coherent commissioning of services. Furthermore, this strategy would help with motivation to identify people at risk as young children and intervene early. Getting support right early would mean people will be significantly less likely to end up in residential or inpatient care due to crisis, leading to less distress for the individual and savings for local authorities.	Thank you for your comment and your support for the recommendation.
Avenues Group	Short	General		General	Overall we feel the guidance is useful and has lots of things right; we believe the aims and principles of the document are beneficial and positive. However, while we believe getting things right at a strategy level is extremely important in delivering good services, we feel the guidance could provide more depth around specifics for services e.g. what exactly should services look like, and what are the potentials for such services?	Thank you for your comment. We did not find high quality research that directly measured the effectiveness of different types of services. The Guideline Committee considered evidence on what good outcomes a service model should achieve and interpreted the available evidence from lower quality research evidence and expert witness testimony with their experience and practice knowledge on what services there would need to be to deliver these outcomes. The effectiveness of specific interventions that services should deliver are in the clinical guideline that accompanies this service guideline and we have referred and hyperlinked to the clinical guideline where appropriate.
Avenues Group	Short	General		General	It would also be good to include information about providing training and support to families as well as employees in the guidance. Experience tells us	Thank you for your comment. We agree that supporting families is important. Parent training programmes are included in the clinical guideline (section 1.7 on psychological and environmental

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					that it works well to train families in the approaches we use in our services, for example positive behaviour support. In many situations behaviour deteriorates when people go home, as an inconsistent response to behaviour leads to confusion. If organisations work with families to support them around the approaches we take, we could avoid this inconsistency.	interventions) that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). Parent training programmes were out of scope for this guideline. We do refer and hyperlink to the clinical guideline where appropriate.
Avenues Group	Short	Gene ral		General	We feel the guidance makes a jump from people living at home, to residential care, to inpatient care but seems to be missing much guidance on supported living. Many of the people we support who have come from secure hospital units are now living in their own homes in the community (supported living) and this is entirely possible with the right support. The guidance should outline what such services could look like, and what the expectations are of social care providers running these services and the employees that work in them. For example, providers should be providing appropriate training for managers and support workers, including de-escalation training and an understanding that this approach should only be used as a last resort, a commitment to positive behaviour support and active support, and an expectation that behaviour that challenges will decrease over time. Essentially, an outline of what these services could look like would be a useful addition to the guidance.	Thank you for your comment. The Guideline Committee agreed on the importance of where people live as a determinant of health and wellbeing. While there was not strong evidence to support a recommendation of one type of housing over another, or the maximum number of residents to maximise choice, control and wellbeing, the committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with. More information on effective interventions for people with learning disabilities for treatment, prevention and management of behaviour that challenges are in the associated clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), which we refer and hyperlink to where appropriate.
British Association for Music Therapy	Short	11	14-27	1.2.3	Music therapy as a psychological intervention through the use of the non-verbal medium of music gives a clear voice to all Service Users whether they have a reliable access to the spoken word or not and therefore can offer support in all ways that are listed in this section of the NICE guidelines. BAMT would be willing to submit case study examples to demonstrate our approach to the NICE shared learning database. Please contact: wendyruck@nhs.net	Thank you for your comment. We have revised the recommendations that list the specialist services that should be made available to providing support. Individual interventions are not in scope for this service guideline but we have referenced the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges) for interventions where appropriate. We will pass this information to our local practice collection team. We will also pass this information to our local practice collection team. More information on local practice can be found here (https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies)
British Association for Music Therapy	Short	12	10-12	1.2.7	Music Therapists can complement the work of Speech and Language Therapists and support the Service User in their communication needs, particularly those Service Users who do not have easy access to the spoken word or for whom words and verbal expression is not available to them. In addition music therapists can aid communication and understanding between the Service User and their family, keyworker, support staff and other professionals through an increase in understanding of non-verbal communication; thereby promoting best quality of care through effective joint working and increased insight and understanding of the Service User's presenting needs. BAMT are concerned that a significant number of Service Users who have behaviour that challenge and do not have access to words may be excluded from specialist health care services that offer meaningful opportunity and treatment in such a way that they can access easily.	Thank you for your comment. Individual interventions are not in scope for this service guideline but we have referenced the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges) for interventions where appropriate. We did not search for evidence in relation to effectiveness of specifics of making a communications assessment because the effectiveness of specific interventions was out of scope for this guideline. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
British Association for Music Therapy	Short	13	12-17	1.2.12	BAMT considers that the one of the roles of a music therapist is to contribute to the development of the PBS plan and provide regular and ongoing support of both a short term and long term nature through the provision of consistent therapeutic support as an integral part of the MDT provision to Service Users. Such contribution will include: assessment and treatment of the underlying causes of a Service Users behaviour; assessment and ongoing support regarding a Service User's communication needs, the provision of a meaningful and accessible creative outlet that benefits the mental health of a Service User in a format that they can use, liaison with the MDT to ensure best quality of care, liaison with family and carers and other support staff, and signposting to other services where other clinical specialisms are required.	Thank you for your comment. This guideline focuses on service design and delivery and we did not review evidence about the effectiveness of particular therapeutic interventions. A separate NICE guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Assessment of challenging behaviour and the development of behaviour support plans are also covered in this guideline.

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British Association for Music Therapy	Short	13	22-28	1.2.14	Music therapy offers a safe space for all communication and self - expression. Access to such expressive and communicative opportunities in a medium that they can use and holds meaning for the Service user will offer them a way of decreasing feelings of frustration and anxiety which will contribute to a decrease in behaviour that challenges. BAMT can offer case study material that demonstrates the role that the music therapist plays in offering interventions to increase communication opportunities. Contact: wendyruck@nhs.net	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
British Association for Music Therapy	Short	15	2-9	1.3.1	BAMT strongly considers that the profession of music therapy should be included in the list of specialist services set down in this NICE guidance. As a member profession of the Learning Disability Senate we are considered to be a central profession in the care of people with a learning disability, supporting the development of and the roll-out of PBS plans and are playing a full role in supporting the current STOMP programme and can offer therapeutic intervention as an effective alternative to the use of medication. BAMT again expresses its concern that there will be a significant number of Service Users who will be excluded from aspects of this guidance owing to their difficulty with the use of the spoken word. Case study examples can be provided. Contact: wendyruck@nhs.net	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
British Association for Music Therapy	Short	16	26-27	1.4.1	Music therapists are Master level trained health care professionals who are able to offer a service to Service Users and their families regardless of their level of cognitive and/or physical abilities. The profession of music therapy has a role to play in the full range of Service User need from the low level to the highly complex individual who may require an in-patient stay or has forensic needs. Equally the music therapist is often a member of the multi disciplinary team who are involved with a Service User offering support and treatment preventing an admission to in-patient services.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically.
British Association for Music Therapy	Short	18	18-30	1.4.5-1.4.6	Again, BAMT is concerned to see that music therapy as a Allied Health Professions is not listed in this document. As members of the Learning Disability Professional Senate and HCPC registered, it is recognised that the music therapist plays an integral part in the healthcare of people with a learning disability and/or mental health problems, including behaviour that challenges. Music therapists offer a cost effective non-pharmacological intervention to support the well-being of Service Users, play a significant role in the use of PBS plans and are viewed as an effective alternative to medication for this client group.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
British Association for Music Therapy	Short	18	6-9	1.4.4	Music therapists work with the Service User and their families in such a way as to assist the Service User and their families in understanding the meaning and underlying cause of the challenging behaviour. Such in-depth understanding is obtained through close observation and 1:1 working with the Service User and can be delivered in a way that is both accessible and meaningful to the Service User. This type of support also extends to other staff groups in the form of	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for

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					consultation and clinical supervision where a greater understanding of someone's non-verbal behaviour is required,	people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
British Association for Music Therapy	Short	7	6-17		The discipline of music therapy is designed and delivered in such a way that supports the NICE aims and principles (as listed on page 7) of this guidance. As a profession we would be willing to submit case study evidence to the NICE shared learning database. BAMT expresses its concern that there may be a significant number of people with a learning disability who do not have verbal communication available to them or for whom it is significantly impaired who will be excluded from these aims due to communication, cognitive and self – expression difficulties or impairments.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically
British Association for Music Therapy	Short	General	General		BAMT expresses its concern that this document does not acknowledge or recognise the contribution of its members to the health and well-being of people (children and adults) who have a learning disability and behaviour that challenges. There is a certain level of unease at the fact this guidance will rely on the Service User having a particular level of cognitive ability to engage with the services recommended which will exclude a significant number of Service Users who have a severe or profound learning disability, many of whom will display challenging behaviour due to their limitations in self - expression and communication. This will have a significant impact on practice and the effectiveness of these guidelines in day-to-day practice for both Service users and their families and the services themselves. Music therapists are able to offer: detailed assessment; treatment; prevention; management; rehabilitation; and crisis intervention of a person with a learning disability (mild, moderate, severe and profound), and additional mental health needs – including challenging behaviour - without having to rely on verbal communication. Detailed observation of the person's use of the creative medium and the relationship that they build with the therapist provides important information for both the care team around them, families as well as the individual themselves which over time may lead to an improvement in mental health when delivered as part of an individualised care package. Music therapists are highly skilled at being able to not only work directly with the individual but the care team and family around them, and this aspect of work is developed as necessary as therapy progresses. We play an integral role in the development of Education and Health Care Plans (EHCP) and Positive Behaviour Support plans (PBS), are a member profession of the Learning Disability Professional Senate and an important supporter of the Stopping Over Medicating People with a Learning Disability or Autism or Both (STOMP) campaign led by NHS England. We offer a cost effective non-pharmological intervention that is accessible to all Service Users and as we are currently present in many community and in-patient teams will not present significant cost implications if included in this NICE guidance.	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered intervention. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.

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					The British Association for Music Therapy members have many years of experience of providing individual and group music therapy to people on the learning disability spectrum with behaviour that challenges, and would be very willing to submit its experiences to the NICE sharing learning database. Contact: wendyruck@nhs.net	
British Association of Art Therapists	Short	15	5	1.3.1	We are concerned that recommending Psychology alone and not 'Psychological Therapies' excludes the possible range of support offered by non-verbal therapies (art, drama, music, play, dance-movement) to those in the person's support network.	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline which accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline 11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies, including music, dance and drama to recommend them specifically. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs
British Association of Art Therapists	Full	16	7	1.3.5	We are concerned that recommending Psychology alone and not 'Psychological Therapies' excludes the possible range of support offered by non-verbal therapies (art, drama, music, play, dance-movement) to those in the person's support network.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline which accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline 11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies, including music, dance and drama to recommend them specifically.
British Association of Art Therapists	Short	17	22	1.4.3	We are concerned that recommending Psychology alone and not 'Psychological Therapies' in Community Learning Disability Teams excludes the possible range of support offered by non-verbal therapies (art, drama, music, play, dance-movement) in understanding the person's communication through challenging behaviour.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline which accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline 11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies, including music, dance and drama to recommend them specifically.
British Association of Art Therapists	Full	18	24	1.4.6	We are concerned that recommending Psychology alone and not 'Psychological Therapies' in Community Learning Disability Teams excludes the possible range of support offered by non-verbal therapies (art, drama, music, play, dance-movement) in understanding the person's communication through challenging behaviour.	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline 11) considered interventions. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
British Association	general	General		General	ELFT Specialist Healthcare Adult Learning Disability Team in Bedford & Luton has several examples of good practice in this area which they would be willing to share.	Thank you for your comment and support for this guideline. Thank you for your response. We will pass this information to our local practice collection team. More information on submitting a local good practice example can be found here.

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of Art Therapists					1. Intensive Support Team (IST) available 24/7 for crisis support which links both the community LD team and the inpatient LD unit. 2. Direct links via shared staff from the IST to the inpatient unit, should someone need short-term admission they have existing relationships with their care team. 3. An evening drop-in crisis café in a local public venue, out of hours, once per week to support increasing wellbeing and social connections in the community and prevent admission to hospital 4. Joint working across the multi-disciplinary team to ensure effective support. Including, Arts Therapy & Psychology input from the Community LD Team to support the family & service user in understanding communication and making sense of the challenging behaviours. Multi-disciplinary development of positive behavioural support guidance, for a full range of challenging behaviour (from low-level to severe). Information gathering is shared across different disciplines, through consultation with Psychology and skilling-up nursing and support staff.	
British Association of Art Therapists	general	General		General	Dr Simon Hackett of Newcastle University and Northumberland, Tyne & Wear NHS Foundation Trust is currently undertaking a randomised control feasibility study to evaluate the use of art therapy with adults with a LD in secure settings to reduce levels of violence and aggression. The early findings of this multi-site study have had a positive outcome for participants and could inform treatment pathways for future service developments. This is also an example of good practice. (Further information on the study outline & protocol available at: http://eprint.ncl.ac.uk/file_store/production/242276/D3A81CF1-0446-4916-AF00-14C0F2E5ECF3.pdf)	Thank you for your comment.
British Psychological Society	Short	10	13	1.1.8	The Society recommends that reference is also made to assistants and professionals in training working under the supervision of qualified specialist professionals, in addition to contact with specialist professionals and the use of specialist professionals in MDT supervision and consultation in addition to direct contact time.	Thank you for your comment. The term 'specialist professionals' is intended to encompass the wide range of people who may provide care and support. This could include staff of different levels of seniority.
British Psychological Society	Short	10	6	1.1.8	The Society believes that reference should be made to satisfaction ratings being completed by schools, colleges and other placements were staff may have to manage challenging behaviour on a day to day basis.	Thank you for your comment. To take into account stakeholder consultation feedback, this recommendation has been updated to include reference to quality of life ratings, as suggested. It also now references quality checks by user organisations and quality review visits from community learning disability teams.
British Psychological Society	Short	12	22	1.2.9	This recommendation assumes that all CLDTs are integrated health and social care teams, this is certainly not the case in nationally and some CLDTs comprise only of health professionals, with social care professionals located in generic child/adult social care teams.	Thank you for your comment. We have revised the recommendation to make it clearer about how local authorities, Clinical Commissioning Groups and service providers need to work in partnership to coordinate care and support.
British Psychological Society	Short	12	22	1.2.9	The recommendation for Local Authorities to allocate a Social Worker to coordinate care would, if it could be implemented, meet a significant need in terms of providing a focal point for a person's care. Current Social Work practice, however, is often episodic in nature, and so once a social care package is stable a case would be closed to Social Services until the annual review. This recommendation would therefore have significant cost implications as additional posts would need to be funded. This role could also not readily be undertaken by other professionals (e.g., health professionals in the community learning disability team) without similar additional resources for the same reason.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. We have recommended that the named practitioner is one of the people already working with the person – not a new member of staff. This means the resource impact will be less. We have also revised the recommendation to make it clearer about how local authorities, Clinical Commissioning Groups and service providers need to work in partnership to coordinate care and support. We also revised the recommendation to say that care and support needs to be coordinated over the long term.
British Psychological Society	Short	13	6	1.2.11	The Society recommends including: □ Undertaking an assessment into the possible risks to the person with learning difficulties, their families and the wider community.	Thank you for your comment. In recommendation 1.2.14, which covers the requirements of the behaviour support plan we reference the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). Recommendation 1.6.1 in the clinical

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					▫ Put in place strategies and provision to manage these risks. (Campbell & McCue, 2012)	guideline makes three references to incorporating risk management into the plan and how it should be carried out.
British Psychological Society	Short	15	2-8	1.3.1	The importance of access to multi-disciplinary support including psychology, SALT and OT is welcomed by The Society. As is the importance of access to positive behaviour support and to training on restrictive interventions and how to reduce their use.	Thank you for your comment and support for this recommendation.
British Psychological Society	Short	15	5	1.3.1	The Society recommends that different professionals and strategies are needed for different causes of challenging behaviour and different types of challenging behaviour. It is therefore recommended that this section be expanded to include reference to: ▫ Difficulties associated with ASD and social communication needs (Rojahn et al., 2010), e.g. changes in routines etc. –professionals involved could include educational or clinical psychologist, learning disability nurses or ASD specialist workers/advisory teachers. ▫ Sensory processing difficulties (Green et al., 2016) – in this case occupational therapy assessment would be appropriate. ▫ Pain/discomfort (Poppes et al., 2016) – liaison with medical services to investigate possible sources of and management of pain. Checking physical comfort e.g. temperature etc. May also include Learning Disability Specialist Nursing. ▫ Frustration/boredom –professionals involved could include educational psychologists or education providers, visual impaired service or hearing-impaired service to ensure there is appropriate enrichment activities at home and school and opportunities to make choices both at home and in settings. ▫ Trying to communicate – professionals involved could include speech and language, EP, learning disability nurse, augmented communication specialists. ▫ Lack of awareness of social skills – professionals involved could include learning disability nurses, educational or clinical psychologists, specialist teachers (e.g. ASD specialists). ▫ Attachment/experiences of trauma/abuse – liaison/assessment from social care, advice from educational and/or clinical psychologists, training for staff and carers. Identify the type of challenging behaviour presented including: ▫ Self – harming – professionals involved could include medical professionals, learning disability nurses, clinical psychologists and or educational psychologists. ▫ Physical aggression towards others – professionals involved could include social services, clinical psychology, educational psychology and if appropriate to their age and ability, the youth offending service. ▫ Sexually inappropriate behaviour – professionals involved could include social workers, sexually inappropriate behaviour services and/or ASD specialists etc.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. We have included a recommendation on training of parents and carers, which states that practitioners should refer to the clinical guideline and provides a hyperlink.
British Psychological Society	Short	15	8	1.3.1	The guidance recommends that specialist services should be sought including 'behaviour analysis and positive behaviour support'; however, these are potentially beneficial approaches that may be delivered by range of professionals, not services.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for

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						people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
British Psychological Society	Short	18	15	1.4.5	The Society recommends a more comprehensive response to offending behaviour developing than simply referring to appropriate specialists such as community forensic teams if risky is needed. The type of support should be determined by the type and cause of the behaviour. Different professionals may be indicated for different causes and therefore a collaborative approach drawing on the skills of both community learning disability teams and community forensic teams may be required rather than one or the other as suggested in the guidance.	Thank you for your comment. We have revised the wording in the recommendation to reflect the need to take a more comprehensive response and to include people at risk of developing offending behaviour. We agree that community learning disability teams (CLDTs) and forensic services should work together. This could be achieved by employing practitioners within the CLDT or by developing close links with practitioners in other relevant services. We hope that the recommendations, if implemented, will encourage greater collaboration between services to deliver services in line with the good practice in this guideline.
British Psychological Society	Short	18	24	1.4.6	The Society recommends offering training and guidance to the police and Accident and Emergency workers on how to identify somebody with learning disabilities and what they need to do to support as well as liaising with the community learning disabilities team. This should be as either a perpetrator or victim of a crime. This should include the need for appropriate adults when questioning a person with learning disabilities and consulting with relevant specialists/professionals about how best to communicate with individuals with learning disabilities (Talbot, 2008).	Thank you for your comment. Training for police and accident and emergency workers was out of scope for this guideline. However, we do recommend in 1.4.6 that Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that: • they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable • people who need support can be diverted from the Criminal Justice Service to community learning disability teams.
British Psychological Society	Short	19	10	1.4.9	It is unclear about the evidence for the recommendation that there should be intensive behaviour support that has the capacity to respond within an hour. There are also clear and highly significant cost and resource issues for providing intensive behavioural support services that could provide a response within an hour 24:7. There is also a concern that in impending such a recommendation may result in services focused on crisis response instead of crisis prevention and proactive working (this links to comment 3 regarding the need to give an equal focus on developing capability in service to reduce the development of challenging behaviour in the first instance rather than a focus on responding once challenging behaviour has developed or in a crisis).	Thank you for your comment. We have revised recommendation 1.4.10 to make clearer that response should be based on an initial 'triage', and that the response of 1 hour is for phone response only. Face to face response is suggested within 4 hours if required following triage and assessment. The resource impact report that considers the costs and benefits of these recommendations, identified providing intensive support in a crisis (after the initial telephone triage assessment) as an area that would likely incur additional costs. However, the evidence suggested that people from a wide range of groups were at more risk of being placed out of area, especially people that had more complex support needs, and providing intensive support during a crisis will reduce the likelihood of people being placed out of their local area. We agree that there should be a greater emphasis on prevention and early intervention. We have strengthened several of the recommendations related to early intervention and prevention. In the aims and principles section we have revised the wording to say 'the guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers'. We have also strengthened the wording and labelling of sections 1.3 on 'support for families and carers' and section '1.4 - services in the community' to reinforce the early intervention and prevention approach We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or inpatient admission due to the lack of available specialist support in the community. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
British Psychological Society	Short	19	12	1.4.9	The Society recommends including: □ A risk assessment with steps undertaken to minimise possible harm to both the individual, their carers, other family members and members of the community.	Thank you for your comment. In recommendation 1.2.14, which covers the requirements of the behaviour support plan we reference the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). Recommendation 1.6.1 in the clinical

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					(Campbell & McCue, 2012)	guideline makes three references to incorporating risk management into the plan and how it should be carried out.
British Psychological Society	Short	19	7	1.4.8	The Society welcomes a maximum wait time. There is a risk however that this could become the standard, it would be helpful to emphasise this is a maximum wait time. Practice examples of how services are designed to meet needs quickly and in line with NICE guidance would be helpful.	Thank you for your comment. We agree that that families should access the right support at the right time. We agree that stating a maximum wait time of 18 weeks can be misread as being the standard, rather than the maximum. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if Recommendation 1.4.9 now states that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support. Where research evidence was lacking, the Guideline Committee invited expert witnesses to give their best practice examples. Where this formed the basis of a recommendation this is discussed in more detail in the 'Evidence to recommendations' section of the full guideline.
British Psychological Society	Short	22	4	1.5.8	In the section, The Society would recommend including: □ Healthy diet (Poppes et al., 2016) and exercise (Hawkins & Look, 2006) □ Having sensory needs met □ Support developing self-care skills □ Support developing emotional regulation and coping strategies (Carr, 2016)	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. This is on the basis that the guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation.
British Psychological Society	Short	23	18	1.6.6	If the persons education, health and care plan is being reviewed, The Society recommends including members of staff from the child or young person's educational setting, and other professionals who have been working with a child including educational psychologists and specialist advisory teachers.	Thank you for your comment. This recommendation has been edited accordingly.
British Psychological Society	Short	26	17	1.8.8	In addition to early identification and brief interventions as stated in NICE, The Society recommends that reference is made to inpatient assessment also offering more in-depth behavioural analysis, e.g. engage in more frequent schedules of observations in a controlled environment using a variety of approaches. This can be helpful in cases where the function of behaviour has been difficult to fully understand in the community, or may have become unsafe to get full functional assessment completed. Also for where there are co-morbidity factors such as a significant mental health factor which might also need treatment, alongside developing a behavioural support plan. This has implications for the service in terms of a skilled MDT who have training in behavioural analysis, and can then use this to formulate a behaviour support plan whilst involving key stakeholders with the view from the start of how the behaviour support plan can be implemented back in the person's home/ community setting.	Thank you for your comment. We have referred to the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), which covers evidence based assessments, behaviour support planning, and intervention.
British Psychological Society	Short	26	23	1.8.9	The Society recommends that this section (1.8.9) is expanded to include lead commissioner to ensure that barriers preventing discharge from inpatient services (i.e. funding) are addressed promptly, to avoid unnecessary lengthy admissions on inpatient wards. Quality of life, well-being and autonomy should also be considered for individuals residing on inpatient wards for long periods; with particular recognition of the psychological impact inpatient admission may have on the individual and their behaviours.	Thank you for your comment. The wording of the recommendations follow on from other recommendations on building capacity in the community which, if implemented, would mean that delays to discharge due to lack of available services and supports in the person's home community would be minimised. The committee's view was also that shifting investment from inpatient to community services would lead to savings elsewhere in the system. We hope that the regular review of discharge planning in recommendation 1.8.9 and 1.8.10 will reduce the time that people are in inpatient care, and then, for only as long as is clinically necessary and useful.
British Psychological Society	Short	26	9	1.8.6	This recommendation would improve the quality of provision for people with learning disabilities. However, in a similar way to the suggestion that Local Authorities should appoint a coordinator, this would represent a significant change in practice for many teams; many services close a case should someone move out-of-area. This recommendation would therefore have	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The Guideline Committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.

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					additional costs associated with it, as teams would need extra funding for this new additional activity.	
British Psychological Society	Short	27	27	1.9.2	The Society welcomes the acknowledgement of the need for staff providing direct support to people with learning disabilities and behaviour that challenges to have training in positive behaviour support.	Thank you for your comment. We are glad that these recommendations will support developments in this area.
British Psychological Society	Short	28	1	1.9.3	'Behaviour support specialists' is not an acknowledged professional title and in the glossary an example of behaviour support specialist provided is a behaviour analyst which is also not an acknowledged professional title in the UK. There is limited evidence to support the effectiveness of behaviour analysts alone, only one study in the long version mentions behaviour analysts and does not demonstrate the effectiveness of the role. The Society recommends rewording the document to remove the terms Behaviour Support Specialist and Behaviour Analyst from the document.	Thank you for your comment. We have removed the term from recommendations when used as a profession title. We have kept the term 'behaviour support' to be a generic term for behavioural interventions that are in line with the evidence-based interventions in the clinical guideline.
British Psychological Society	Short	5	4	Background	In considering the statement "In particular this aims to shift emphasis from inpatient care in mental health hospitals, towards care provided by general and specialist services in the community" it should be noted that the proportion of individuals in inpatient care is only a small proportion of those with learning disabilities and challenging behaviour, with the vast majority of residing in community settings. While Winterbourne View was a driver for policy and practice recommendations it is suggested that the context of the majority of individuals who the guidance applies to is in the community and furthermore the risk of abuse within community setting still exists and is not just limited to inpatient settings.	Thank you for your comment. We have revised the text to be in line with the aims of transforming care, although a reduction on the reliance on inpatient services would be the likely outcomes, the Aims and Principles now read: 'The guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers. This should reduce the need for people to move away for care and treatment'.
British Psychological Society	Short	8	15	1.1.3	Pooled budgets and sharing resources to develop local and regional services are welcomed by The Society and reflects work completed within Transforming Care Partnerships across the country.	Thank you for your comment and support for this recommendation.
British Psychological Society	Short	8	19	1.1.4	The recommendation for a 'contingency' fund is helpful. However, The Society believes that providing examples of how this has worked in practice and additional resources to guide services in this area would be helpful.	Thank you for your comment and support for this recommendation. The wording of this recommendation reflects the evidence presented by the expert witness. This is discussed in more detail in the full guideline, in the section on 'Evidence to recommendations'. We have added a definition in the terms used section. It is not NICE house style to include practice examples within the guideline itself. However, NICE do develop materials to support implementation of the guideline.
British Psychological Society	Short	8	3	1.1.1	This section advising on a single joint commissioner across health and social services, in providing leadership and focus at a commissioning level on developing and monitoring services and managing risk is welcomed by The Society. This is a key starting point in improving service provision and is likely to reduce the barriers to working effectively across the health and social care system. It is suggested that consideration of the significant period of transition between child and adult services could be highlighted further given there is evidence that this is also the point at which onset of behaviour that challenges is most prevalent.	Thank you for your comment. Reference to transitions has been added to recommendation 1.1.2.
British Psychological Society	Short	9	17	1.1.6	This poses a significant change to current ways of working in many areas and will potentially have significant cost implications in terms of resourcing required. Examples of practice, where this is current practice would be helpful. Cross reference to the section of respite care (page 24 line 23) would be helpful.	Thank you for your comment. The Guideline Committee were aware of the variation in practice nationally. The first section of the guideline therefore addresses what needs to change to achieve better access and quality of services for people and their families, and how services should be organised and commissioned. The section on Achieving Change (1.1) focused on solutions to problems identified in the research literature.

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						The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable. Further information on how the guideline committee reached consensus on these recommendation in Achieving Change are discussed in more detail in the 'Evidence to recommendations' section in the full guideline. It is not NICE house style to include practice examples within the guideline itself. However, NICE do develop materials to support implementation of the guideline. There is a chapter on short breaks (the term is preferred over 'respite'). We have not included a cross-reference, but this will be clearly marked in the navigation for the guideline.
British Psychological Society	Short	General		General	The Society welcomes this guidance on service design and delivery for people with learning disabilities who engage in behaviour that challenges this document and hopes that it will drive change in services for children and adults with learning disabilities whose behaviour can become challenging. It is hoped that the full implementation of this guidance across learning disabilities services would significantly improve practice and outcomes for people with learning disabilities.	Thank you for your comment and support for the guideline.
British Psychological Society	Short	General	General		The Society recommends referencing of proactive approaches to challenging behaviour and the role that services have in developing support for individuals with learning disabilities that reduce the chances of challenging behaviour developing in the first instance. There is a clear evidence base pertaining to individuals who are more at risk of presenting with behaviour that challenges, based on prevalence rates of challenging behaviour. Focused and targeted training, service developments, supervision and consultation in collaboration with specialist professionals may reduce the chances of challenging behaviour developing. At present the guidance appears to focus on what services should be doing once challenging behaviour has developed and/or when a there is a crisis rather than what can be done to avoid its occurrence.	Thank you for your comment. The guideline aims to make recommendations about prevention and early intervention in relation to behaviour that challenges, as well as actions after it has arisen. We have strengthened several of the recommendations related to early intervention and prevention. In the aims and principles section we have revised the wording to say 'the guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers'. We have also strengthened the wording and labelling of sections 1.3 on 'support for families and carers' and section '1.4 - services in the community' to reinforce the early intervention and prevention approach.
British Psychological Society	Short	General	General		The Society believes that more reference to the physical health needs of people with learning disabilities is needed. Specifically, how these are proactively assessed and how people are supported to access physical health services in order to avoid experiencing pain associated with physical ill health which in turn may lead to the development of challenging behaviour.	Thank you for your comment. Reference to physical health has been added in to the overarching principles for the guideline. Physical healthcare is covered in detail in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
British Psychological Society	Short	General	general		**References** Campbell, M., & McCue, M. (2012). Assessment of Interpersonal Risk (AIR) in adults with learning disabilities and challenging behaviour—piloting a new risk assessment tool. British Journal of Learning Disabilities [online]. **41(2)**:141-149. **[in EPPI, EXC on intervention]**	Thank you for your comment. Please note that the focus of this guideline was on service design and delivery, and this was reflected in our search strategy and review protocols. The following papers were identified by our searches, but excluded as they were about interventions (and so were out of scope for this service guideline) • Campbell and McCue (2012) • Rojahn et al. (2010). The following paper was excluded on topic: • Talbot (2008).

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					Carr, A. (2016). *Handbook of Child and Adolescent Psychology: A contextual approach (third edition).* Oxon: Routledge**.** **[not in EPPI, doesn't look relevant]** Green, D., Lim, M., Lang, B., Pohl, K., & Turk, J. (2016). Sensory processing difficulties in opsoclonus-myoclonus syndrome: a pilot project of presentation and possible prevalence. *Journal of child neurology*, *31***(8)**, 965-970. **[not in EPPI, also just a Pilot Project of Presentation and Possible Prevalence]** Hawkins, A., & Look, R. (2006). Levels of engagement and barriers to physical activity in a population of adults with learning disabilities. *British Journal of Learning Disabilities*, *34***(4)**, 220-226. **[Not in EPPI, not on topic]** Poppes, P., Putten, A. J. J., Post, W. J., & Vlaskamp, C. (2016). Risk factors associated with challenging behaviour in people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, *60***(6)**, 537-552. **[Not in EPPI]** Rojahn, J., Wilkins, J., Matson, J. L., & Boisjoli, J. (2010). A comparison of adults with intellectual disabilities with and without ASD on parallel measures of challenging behaviour: The Behavior Problems Inventory-01 (BPI-01) and Autism Spectrum Disorders-Behavior Problems for Intellectually Disabled Adults (ASD-BPA). *Journal of Applied Research in Intellectual Disabilities*, *23***(2)**, 179-185. **[in EPPI, EXC on intervention]** Talbot, J. (2008). Prisoners' Voices: experiences of the criminal justice system by prisoners with learning disabilities and difficulties. *London*: *Prison Reform Trust* **[in EPPI, EXC on topic]** British Psychological Society	The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Most of the suggested references are about prevalence and measuring behaviour that challenges which was considered in the clinical guideline.
Buckinghamshire County Council	Short			General	Not enough around ensuring people receive their legal rights in relation to Human Rights Act, DOLS and ReX restrictions	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation. We have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation. We have added the Human Rights Act and the Mental Health Act to the list of relevant legislation. Recommendation 1.1.10 says that commissioners should use reports of restrictive interventions as an indicator of quality service when choosing service providers. We note that The Department of Health and Department of Education is currently consulting on draft guidance on reducing the need for restraint and restrictive interventions for children and young people with learning disabilities, autistic spectrum disorder and mental health needs.
Buckinghamshire County Council	Short			General	Reference to MCA very fleeting when in actuality DOLS and ReX restrictions are having enormous impacts on care provision	Thank you for your comment. We agree that people should be active participants in all aspects of their care and any decisions made that affect them. A NICE Guideline on Decision making and mental capacity [GID-NG10009] is in development and is due for publication 16 May 2018. This guideline will help health and social care practitioners who are supporting people who may lack capacity to make decisions about their health and social care needs. This may include decisions about where and how people live, their support, care and treatment and their security or safety.

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						We agree it is useful to highlight how the guideline relates to other guidance and legislation. We have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation. We have added the Human rights act and the Mental Health Act to the list of relevant legislation. Recommendation 1.1.10 says that commissioners should use reports of restrictive interventions as an indicator of quality service when choosing service providers. We note that The Department of Health and Department of education is currently consulting on draft guidance on reducing the need for restraint and restrictive intervention for children and young people with learning disabilities, autistic spectrum disorder and mental health needs.
Buckinghamshire County Council	Short			General	MHA and s117 aftercare not referenced in any meaningful way	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation. We have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation. We have added the Human Rights Act and the Mental Health Act to the list of relevant legislation. Recommendation 1.1.10 says that commissioners should use reports of restrictive interventions as an indicator of quality service when choosing service providers. We note that The Department of Health and Department of Education is currently consulting on draft guidance on reducing the need for restraint and restrictive intervention for children and young people with learning disabilities, autistic spectrum disorder and mental health needs.
Buckinghamshire County Council	Short	12		1.2.9	1.2.9 Idea of a named worker is just not realistic. Given the definitions of the cohort and the numbers of people given in Background context – 1.2mill with 10% in cohort with a caseload of 20 people would require 6000 named workers in LD services across the country – not realistic!! And ignores the need of the other 90% of the LD population. If advised named worker responsibility is not just on LA to have a named worker; recommend to include NHS.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. We have recommended that the named practitioner is one of the people already working with the person – not a new member of staff. This means the resource impact will be less. We have also revised the recommendation to make it clearer about how local authorities, Clinical Commissioning Groups and service providers need to work in partnership to coordinate care and support.
Buckinghamshire County Council	Short	14		1.2.16	1.2.16 LA's do not offer personal health budgets so need to include NHS in this section	Thank you for your comment. We have revised recommendation 1.2.19 to read that local authorities and clinical commissioning groups need to 'ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences'. Think about using integrated personal commissioning where it is available to support this'.
Buckinghamshire County Council	Short	15		1.3.1	1.3.1 This section lists NHS services so it should be NHS responsibility to enable access to them – not LA.	Thank you for your comment. We have revised this recommendation to read: 1.3.1 Local authorities should ensure that parents families and carers of children, young people and adults with a learning disability and behaviour that challenges have support to care for that person from specialist services working with the person, including those covering needs relating to care and support, communication, physical health, mental health, educational needs and any offending behaviour. This section is followed by 1.4 Services in the community – prevention, early intervention and response, which gives more detail of who should do the commissioning of these services, the lead commissioner which we have described as a role that oversees the strategic commissioning for both health and social care.
Buckinghamshire County Council	Short	17		1.4.3	1.4.3 Forensic services are commissioned by NHSE not CCG's.	Thank you for your comment. We have checked with two commissioners, as well as the Transforming Care specifications, which confirmed that community forensic learning disability teams are commissioned locally, but that there is an NHS England specification of what they should include. We have revised 1.4.12 to make it clearer that forensic services could be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning disability team.
Buckinghamshire County Council	Short	19		1.4.9	1.4.9 An LD specific Out of Hours on call would not be affordable or practical in many areas – and the only likely response within 1 hour would be a phone call. Not realistic or affordable.	Thank you for your comment. We agree that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed.
Buckinghamshire County Council	Short	21		1.5.5	1.5.5 Shared housing with max of 3 people is not realistic or affordable or appropriate in every case. Too restrictive in guidance.	Thank you for your comment. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. The Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more like an ordinary home for most people. The

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						Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, homelike environments with people having a choice over who they live with.
Buckinghamshire County Council	Short	22		1.6.3	1.6.3 No mention of working with family as well	Thank you for your comment. The aim of this recommendation is to ensure that practitioners work together collaboratively. The Guideline Committee agree that it is essential that practitioners also work with families and carers and have emphasised this in section 1.2.
Buckinghamshire County Council	Short	25		1.8.2	1.8.2 Not always appropriate or possible to have expert by experience if admission is result of a crisis over a short period of time	Thank you for your comment. The Guideline Committee recognise that this may not always be appropriate or possible; however they thought it important to recommend and highlight best practice, based on the research evidence.
Buckinghamshire County Council	Short	26		1.8.7	1.8.7 Not just a social worker role – widen it to include health and social care workers.	Thank you for your comment. The Guideline Committee agree that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff.
Buckinghamshire County Council	Short	8		1.1.1	1.1.1 Single lead commissioner role is too big for one person and will have too many overlaps with other commissioning roles eg education, SEN, early help, working age adults etc.	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Buckinghamshire County Council	Short	8		1.1.1	1.1.1 By limiting commissioning role to only someone who has direct experience of working with people with behaviour that challenges services you are limiting the talent pool for the role. Also given level of post it is unlikely that anyone would have much recent experience so it would be out of date.	Thank you for your comment. The view of the Guideline Committee was that experience of working with people with behaviour that challenges was needed for this role to understand the specific needs of people with learning disabilities and behaviour that challenges and the challenges they currently face in accessing services across different sectors, in a seamless, person-centred way. The Guideline Committee did not state that the experience had to be recent but that like all staff, should be based on the best available evidence and guidance on working with people with a learning disability and behaviour that challenges (see section 1.9 on staff skills and values).
Buckinghamshire County Council	Short	8		1.1.3	1.1.3 Pooled budgets have a specific meaning and implication of the s75 agreement requiring legal agreement between organisations which is not always likely; recommend use of 'aligned' budget.	Thank you for your comment. We understand that there are both aligned and pooled budgets. Research evidence considered by the Guideline Committee has suggested that the benefits of pooled budgets are not yet being realised and for this reason mention pooled budgets in our recommendation specifically. Pooled budgets are recommended as an important mechanism of integrating health and social care. We have revised recommendation 1.1.3 to make clear this is in line with the Transforming Care Agenda.
Buckinghamshire County Council	Short	8	16	1.1.5	1.1.5 Recommend use of aligned not pooled	Thank you for your comment. We understand that there is a difference between aligned and pooled budgets. Research evidence considered by the Guideline Committee has suggested that the benefits of pooled budgets are not yet being realised and for this reason mention pooled budgets in our recommendation specifically. Pooled budgets are recommended as an important mechanism for integrating health and social care. We have revised recommendation 1.1.3 to make clear this is in line with the Transforming Care Agenda.
Buckinghamshire County Council	Short	General		1.1.7	No mention of risk assessments – critical for this cohort	Thank you for your comment. We have revised recommendation 1.4.8 to include assessments of both need and risk. Specific risk assessments are referenced in section 1.5.7 on risk assessment in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have referenced the clinical guideline where appropriate
Care England					.	*There was no text in this comment.*
Care England	Short	1		General	We welcome the fact that the guideline recommends a range of services however this is not then reflected within the document itself which for example largely ignores residential care services. The guidelines are therefore limited in their effectiveness and reach.	Thank you for your comment. We have not excluded residential services, but prefer to say that, whatever the person and their families choose, it should be based on their choice and not because local services are not available. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
Care England	Short	10	11	1.1.8	Local community concerns need to be taken into account and some individuals may prefer a quieter location than being too close to others within a community. Tenancies also do not always protect people from being evicted once terms of the tenancy have been broken.	Thank you for your comment. The Guideline Committee agreed a stand-alone recommendation focused on security of tenancy, referencing the Real Tenancy Test (recommendation 1.5.3). The remaining recommendations seek to distinguish service provision from housing and emphasise the need to ensure housing is personalised to support needs and personal preferences.

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Care England	Short	10	2	1.1.8	There are some useful outcome measurement tools in social care but they can be difficult to use and a realistic approach to what can be achieved for an individual over time is necessary accepting that sometimes there will be set backs. QA should not be driven by cost reduction aims.	Thank you for your comment. The Guideline Committee was also concerned about the financial context and budgetary constraints. It hopes that the recommendations of this guideline will help advocate for quality assurance mechanisms based on evidence from this work, rather than driven by cost reduction aims.
Care England	short	11	14	1.2.3	We welcome that the support highlighted in 1.2.3 is about relationships and ensuring staff with positive values and attitudes delivering a service and not about buildings and bed numbers.	Thank you for your comment and support for this recommendation.
Care England	Short	11	3	1.2.1	Care England agrees that staff working with people with learning disability and behaviour that challenges have a key role to play in enabling person-centred care. The large majority of such staff work with providers in the independent sector rather than within statutory services (excluding in-patient services), but there is little attempt made to extract the experience and evidence such staff are able to offer in practice. Care England would welcome a stronger emphasis on the advantages o**f including providers in all such discussions**, particularly in terms of establishing the appropriate outcomes frameworks against which provision of services can then be measured.	Thank you for your comment. The emphasis of this recommendation is that staff should get to know the person they support and find out what they want from their lives, not just what they want from services. This is applicable to all staff working with the person and their families whether in the NHS, voluntary or independent sectors. The outcomes framework defined for commissioners in recommendation 1.1.10 will be monitored by a multi-agency group that includes service providers (recommendation 1.1.12).
Care England	Short	13	1	1.2.11	Care England agrees with much of what is contained in the section on Care and Support Planning; and again emphasises the role that service providers have and are able to offer in this context. Care England notes that the recommendations are "setting blind" in that it is not the setting which determine whether good care and support is offered, but the culture which is created and Care England strongly endorses the emphasis on this.	Thank you for your comment and your support for the guideline.
Care England	Short	14	10	1.2.16	Care England believes that a more sophisticated approach is required to cover circumstances in which direct payments may be offered. The Guidance needs to make it clear that, prior to setting a direct payment budget, it is incumbent upon the local authority to carry out a formal care needs assessment and to identify what the appropriate setting for the individual might be (in conjunction with them and their family). In straightened times there is a real risk that local authorities will make assumptions around offering non-residential services because that reduces their budget, as housing support costs then come from a different budget which are not met through a direct payment. The perverse incentives offered to local authorities in this way are part of the economic picture which should be addressed as part of the Guidance, to at least alert commissioners to the dangers of not following their responsibilities under the Care Act 2014. NICE should have regard to the economic interests of the taxpayers for which the total costs across services not just costs to individual budgets are relevant.	Thank you for your comment. We have revised recommendation 1.2.19 to read that local authorities and clinical commissioning groups need to 'ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences'. Think about using integrated personal commissioning where it is available to support this. The Guideline Committee was also concerned about the financial context and budgetary constraints. It hopes that the recommendations of this guideline will help advocate for the commissioning, or continued investment in, evidence-based services. This is in line with The Care Act that places a duty on local authorities to integrate health social care and other health-related services where this promotes wellbeing.
Care England	Short	16	21	1.4	The section on Developing Community Capacity does not cover all services; there is no reference to residential services for adults and it would be helpful to clarify the role of residential services at paragraphs 1.4.1 and 1.4.2. and indeed throughout the guideline. The guideline needs to be clear on the definition of residential care and that such provision is part of the local community. It should not for adult care be deemed as in children's care to be a service of 'last resort'.	Thank you for your comment. We have defined what we mean by 'residential placement' in the context of this guideline in the list of terms section. It makes clear that a residential care home for adults is an example of a residential placement. The Guideline Committee felt strongly that it was more important that people had a choice over where they lived, that the type of accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. The Guideline Committee interpreted this evidence and evidence from the expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home-like and is more like an ordinary home for most people. The Guideline Committee favoured accommodation which offered security of tenure and a split between supported service provision and accommodation.
Care England	short	19	17	1.4.9	The impact of living at home should also consider the impact for the wider family not just the individual.	Thank you for your comment. The recommendation covers providing a personalised approach which could include taking into account the impact of living at home.
Care England	Short	20	19-20	1.5	1.5 Should be just titled Day to Day Support: Giving people a choice of accommodation and support.	Thank you for your comment. Following feedback from stakeholders we revised the section heading to read 'housing and related support'.

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Care England	Short	20	23	1.5.1	The guideline fails to acknowledge that the range of accommodation options available currently includes significant amounts of appropriate good quality residential care homes which are appropriate for certain individuals, whether by virtue of the care needs they have or by virtue of the choice they have made, and the likelihood is that there will be a continuing requirement for residential care services which, if they continue to be overlooked in the guidelines, will not be subject to the same evidential review that Care England supports.	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, the Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more like an ordinary home for most people. The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation.
Care England	short	20	3	1.4.11	There is no mention of the model forensic services will take or indeed how community provision e.g. through private landlords will address anxiety of and risk to the individual.	Thank you for your comment. We have revised recommendation 1.4.12 to provide some examples of how services could be configured. In addition, recommendation 1.5.1 covers working with local housing providers to identify the specific housing needs of adults with a learning disability and behaviour that challenges and ensuing that a range of options are available that meet these needs and cater for different preferences and person-centred support needs.
Care England	Short	21	11	1.5.5	Care England has concerns around the apparent presumption on the part of certain commissioners that supported living automatically solves problems of "institutionalisation" which are created by large settings (whether in large residential institutions or in-patient services). NICE appear to have acknowledged that there is no actual evidence for such presumptions at present, but has highlighted the need for research to be carried out to verify the correct approach required to commissioning practice. There should be no narrow focus for searching for evidence only in relation to supported living or shared lives services but instead encompass residential care also. Care England members note that certain formats for supported living create "institutionalisation" just as certain in-patient or large scale residential care services do not, and that the model itself is not any determinant of quality in terms of the outcomes or the lives that people with learning disabilities and behaviour that challenges are able to achieve in supported living settings. There is real current evidence on quality of outcomes for people in residential services through the CQC where such services have been awarded 'outstanding' ratings see: http://www.cqc.org.uk/location/1-2847234051 http://www.cqc.org.uk/location/1-122256185 http://www.cqc.org.uk/location/1-120732790 Care England would not wish to see any arbitrary judgements made about these issues and questions whether the reference in this paragraph to "3 other residents" has any real meaning. Where is the evidence to back up this number? It would be helpful to understand why this number was chosen unless it was based on the assumption that only relatively small numbers of houses are available to groups of more than 4 people. This section applies to supported living so the term used should be tenants not residents.	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. It was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The cost effectiveness research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another or the optimum or maximum number of residents that could be specified that would be suitable for everyone, for this reason the reference to a specific number has been deleted. The Guideline Committee interpreted the available research evidence that congregating people together based on their behaviour that challenges and not based on their preferences or compatibility with other residents achieved worse outcomes, and cost effectiveness evidence that it was no more cost effective to group more than 6 people together. Evidence from expert witnesses together with their practice and experiential knowledge indicated that small numbers were more like an ordinary home for most people where people had a choice over who they lived with. The Guideline Committee agree that there was a lack of information on the most cost effective forms of accommodation and have developed a research recommendation to address this as a priority for future research. This section is about all kinds of accommodation, including residential, so the term residents is retained.
Care England	Short	22	10	1.6	There is a section on services for children and young people which makes specific reference to residential care being an offer of last resort. Care England is concerned that this could be read across to cover adult services as well, and would welcome clarification that no such approach should be adopted. Children and adults services are not the same and should not be presumed to be so.	Thank you for your comment. After reviewing the recommendation, we think that it is clear that this relates specifically to services for children and young people.
Care England	short	23	9	1.6.5	A residential placement needs defining more clearly than the limited definition at page 30. Residential care can cover a wide variety of services.	Thank you for your comment. After careful consideration, we think that providing a small number of illustrative examples is more appropriate than trying to compile an exhaustive list of all settings.
Care England	Short	24	1 - 30	1.6.8, 1.6.9,	We welcome the proposals in this section.	Thank you for your comment and support for these recommendations.

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				1.6.10, 1.6.11, 1.7.1		
Care England	Short	25	13	1.8	Care England strongly endorses the need for in-patient services to be used sparingly and only in the right circumstances. Care England believes that very few permanent in-patient placements are appropriate and assessment and treatment options should be exactly that – should be time limited. Care England would like to highlight that in-patient services are too frequently used because of a lack of suitable provision in the community due to :- □ Inconsistent commissioning □ Regulatory changes that act as a huge disincentive to providers to develop quality specialist services A number of Care England members who are leading specialist providers are reducing or stopping plans for building new services because of the CQC implementation of 'Registering the Right Support'	Thank you for your comment. We hope that the guideline will lead to more appropriate use of inpatient services. It is beyond the remit of NICE guidance to make recommendations about regulatory frameworks.
Care England	Short	27		1.9	1.9 We welcome the focus on staff skills and values but feel we want to emphasise that staff need good providers with a strong infrastructure to provide the support they need to do their job well – yet the provider role is not mentioned. A good provider will ensure there is training, crisis teams, PBS training, leadership, quality assurance framework and monitoring and good communication at all levels of the organisation. We would support a whole new section on the role of providers in whole system working and as partners in delivery and contributing to high quality care.	Thank you for your comment. We have not made a separate section on providers but have included these elements of good practice in other recommendations. As a service model guideline, we have directed many of these recommendations to commissioners of services, to make sure that their role includes ensuring good practice by service providers, particularly in section 1.1 on Achieving change and recommendations 1.1.10 to 1.1.13 on quality assurance for commissioned services.
Care England	Short	27	25	1.9.2	Reference should be made to the PBS Academy http://pbsacademy.org.uk/	Thank you for your comment and your support for the guideline. A hyperlink to the Positive behaviour support competence framework. is provided for people to find more detailed information.
Care England	Short	30	14	Putting into practice	This recommendation will only carry any weight if the law is changed to oblige commissioners to integrate services or to give individuals sufficient easily-attained rights. This will ensure the cooperation of commissioners to fund services they can arrange for themselves. We question how a single lead commissioner for children and adults would work and are there people who would have the knowledge and skills to do such a role?	Thank you for your comment. While changes to the law to enforce greater integration of services is outside of NICEs' remit. The ambitions of the Transforming Care policy and programme is towards greater integration of health and social care. The Guideline Committee considered the feedback on the Lead commissioner role, and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Care England	Short	31	6	Putting into practice	Care England believes strongly that the required increase in capacity in services and accommodation will only occur if there is strategic commissioning in which local authorities and CCGs are committed to long-term support for the development of services which will then have sufficient support to enable them to be properly funded. This needs to acknowledge that accommodation costs are different in different parts of the country which impacts on finding homes for people but also staff to provide the care and support.	Thank you for your comment. We have referred to NHS England in reference to the policy context of Transforming Care in response to the Transforming Care report: a national response to Winterbourne View Hospital (Department of Health 2012). The report calls on local authority and NHS commissioners to use integrated commissioning arrangements to transform care for vulnerable adults with learning disabilities and autism, and mental health conditions or behaviours described as challenging. This guideline takes into account the direction of travel in Transforming Care. It aims to complement this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges.
Care England	Short	33	4	Research recs	Care England strongly agrees that research is vital to avoid arbitrary judgements being made about what is or is not suitable in terms of service provision which in turn restricts choice and/or cannot be delivered cost effectively. Care England does not believe this is necessarily a matter of compromise between quality and cost, but NICE should introduce a degree of realism into the debate to ensure that better services are available than are currently available. Good evidence (of the type recommended for research) will significantly assist this. Care England would welcome a commitment by NICE to commission and publish the research promptly for the benefit of all agents in service design and delivery so that services can be developed which	Thank you for your comment. The Guideline Committee agree that people should expect recommended health and social care services and interventions to be based on the best available evidence and that services should be personalised and person-centred, and in that sense there is no one model of care. We agree that there was a lack of direct, robust research evidence on the effectiveness and cost effectiveness of different kinds of models of service delivery for people with learning disabilities and behaviour that challenges. Research into social care provision and models of health and social care service provision is in its infancy. In addition to the research evidence of effectiveness and cost effectiveness, Guideline Committees brings different kinds of knowledge from their professional experiences and the knowledge of people with lived experience of services. They can request evidence

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					deliver good outcomes and choice and control which are supported by that evidence. Given the very small amount of published research, which in itself the consultation acknowledges is "limited", about what configurations of services and resources provide the best form of support, it would be helpful for NICE to reiterate this gap in knowledge and emphasise that any arbitrary limitations, whether by commissioners or CQC (in terms of the registration of services), should be resisted and greater weight given to the choices made by the individuals concerned to meet their assessed needs. Indeed no research should just focus on supported living or shared lives but look at all accommodation options including residential care. Also any attempt to apply research that is about the client group outside of this guideline is flawed in our view. Until a significant evidence base is achieved there should not be a prescribed service model put forward.	from expert witnesses where there are gaps in the research literature and make recommendations for future research. The guideline is based on the best available evidence at this time. The guideline committee made two research recommendations covering the effectiveness and cost effective of different types of support for (i) people with learning disabilities and behaviour that challenges, and (ii) family members, carers and staff. Research recommendations developed by guideline committees are reviewed by the National Institute of Health Research (NIHR) and inform research priorities for NICE and other commissioners and funders of health and social care research.
Care England	Short	34	3	Research recs	See comments directly above.	Thank you for your comment. The Guideline Committee agree that people should expect recommended health and social care services and interventions to be based on the best available evidence and that services should be personalised and person-centred, and in that sense there is no one model of care. We agree that there was a lack of direct, robust research evidence on the effectiveness and cost effectiveness of different kinds of models of service delivery for people with learning disabilities and behaviour that challenges. Research into social care provision and models of health and social care service provision is in its infancy. In addition to the research evidence of effectiveness and cost effectiveness, Guideline Committees brings different kinds of knowledge from their professional experiences and the knowledge of people with lived experience of services. They can request evidence from expert witnesses where there are gaps in the research literature and make recommendations for future research. Research recommendations developed by guideline committees are reviewed by the National Institute of Health Research (NIHR) and inform research priorities for NICE and other commissioners and funders of health and social care research. The guideline is based on the best available evidence at this time. Research recommendations developed by guideline committees are reviewed by the National Institute of Health Research (NIHR) and inform research priorities for NICE and other commissioners and funders of health and social care research.
Care England	Short	4	16	Background	The point is made that the context is one of a changing policy and practice environment. We would welcome recognition that people using services are entitled to have services which are proven to result in improved outcomes. Care England strongly welcomes the recognition that significant additional research is required to ensure that determining the appropriateness of providing support is based on evidence. Indeed we would welcome the opportunity to contribute to research across all care models. Care England providers are prepared to give the time and commitment to share their experiences of providing pioneering new services across all settings. We strongly believe that the principle should be to evidence person centred services and that there cannot simply be one model that delivers such care.	Thank you for your comment. We agree and have revised the text in the background section to say this more explicitly. It now reads: "This guideline was developed in a context of developing policy and practice" The Guideline Committee agree that people should expect recommended health and social care services and interventions to be based on the best available evidence and that services should be personalised and person-centred, and in that sense there is no one model of care.
Care England	Short	4	20	Background	Mansell 2 made it clear that it was the culture in which services were provided which was a greater indicator of quality than either location or size, provided the services were near to communities generally and to those in which people were originally based. Care England strongly endorses the idea that the approach of the Care Act towards person-centred care and giving individuals as much choice and control over their services as possible should be thoroughly endorsed by the Guidance. Having a strong value base within services backed by an organisational infrastructure that encourages and	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. It was more important that people had a choice over where they lived, that the type of accommodation offered was based on their needs and preferences and offered a choice about who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. The Guideline Committee interpreted this evidence and evidence from the expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home-like and is more like an ordinary home for most people.

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					supports innovation and good practice is key. We hope the guideline can be explicit that size is not the most important issue in ensuring quality and outcomes.	The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation.
Care England	Short	4	23	Background	Care England is of the strong view that it has been inconsistent and non person-centred commissioning which has led to the increased use of placements away from people's homes in a way that allowed Winterbourne View and other poor outcomes to happen, and which perpetuates circumstances in which inappropriate care is being provided. It is Care England's view that such inconsistent commissioning practice continues to be the main reason why the transformation sought following Winterbourne View has not been achieved. Care England would support strong guidance from NICE which encourages commissioners to ensure that adequate services are available in their locality to meet the needs of the relevant service users. However as one size does not fit all, and family should also have a choice to look out-of-area, then if the right service is not available in county then other options should be available if the family feel this is manageable for access and contact.	Thank you for your comment. The Guideline Committee agree that commissioning of local services was central to a model of service delivery that was person-centred. The Guideline Committee considered the research evidence on out-of-area placements and people's views and experiences of services to develop the role of a single lead commissioner. The recommendation has been amended to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity. We hope that the implementation of these recommendations will mean that local services are available and that families do not have to choose to send their family member out-of-area because there are not services available locally.
Care England	Short	5	14	Background	The National Service Model and Service Specifications do not easily translate into service specifications for the full range of services actually required to deliver services for people with a learning disability and behaviour that challenges. Care England would welcome recognition that a more inclusive model service specification in which the approach centred on the development of "capable environments" took a more prominent role. This would see distinctions between particular registration categories for services (such as those which exist between supporting living services and residential care services) given less prominence compared with the environment in which the services operated, with a particular emphasis on that environment encouraging good outcomes for service users within the overall choice and control agenda. The need for Transforming Care to expand its evidence base to ensure that there is clarity around what constitutes both the right outcomes as well as what constitutes a capable environment, should take more prominence in both the Transforming Care programme and NICE's guidelines.	Thank you for your comment. The Guideline Committee agreed on the importance of people's environments as a determinant of health and wellbeing. Both "capable" and "challenging" environments are considered in the clinical guidelines, (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), as a review question: In people with a learning disability and behaviour that challenges, what are the benefits and potential harms associated with environmental changes aimed at reducing and managing behaviour that challenges? We have revised recommendation 1.5.4 to refer and hyperlink to this section for people who wish to know more. In reviewing the evidence on housing, as a service guideline we did not find strong evidence to support a recommendation of one type of housing over another, or the maximum number of residents to maximise choice, control and wellbeing. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with. The Guideline Committee favoured accommodation which offered security of tenure and a split between supported service provision and accommodation.
Care England	Short	5	22	Background	We note that cost effectiveness is required. We note that NICE is not seeking evidence which supports any arbitrary limits on the number of service users either within a residential care facility or supported living facilities. We note from the evidence review that significant work was done to identify whether such things as congregate or non-congregate settings produced better outcomes, but Care England believe that a more rigorous approach to collecting evidence which looks at cost effectiveness "in the round" across all services is necessary. Care England request that NICE give more clarity about the importance which cost effectiveness has in the application of this Guidance, particularly in terms of where the balance between cost effectiveness and service provision should be struck. Care England providers must run viable and sustainable services, which as settings get smaller and the complexity of care greater, becomes harder to achieve. Sustainable services are especially necessary to ensure good staff recruitment and retention and to allow staff rotation to protect staff from undue stress. Finally a viable service ensures providers can attract further investment for future innovation, including technology enabled care.	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. It was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The cost effectiveness research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another or the optimum or maximum number of residents that could be specified that would be suitable for everyone, for this reason the reference to a specific number has been deleted. The Guideline Committee interpreted the available research evidence that congregating people together based on their behaviour that challenges and not based on their preferences or compatibility with other residents achieved worse outcomes, and cost effectiveness evidence that it was no more cost effective to group more than 6 people together. Evidence from expert witnesses together with their practice and experiential knowledge to indicate that small numbers were more naturally home like, and more like an ordinary home for most people. The Guideline Committee agree that there was a lack of information on the most cost effective forms of accommodation and have developed a research recommendation to address this as a priority for future research. Research recommendations developed by guideline committees are reviewed by the National Institute of Health Research (NIHR) and inform research priorities for NICE and other commissioners and funders of health and social care research.

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Care England	Short	5	5	Background	Transforming Care rightly identified the need to have a range of services provided in the community. Care England endorses the need for a variety of services and notes that NICE have clarified within the draft consultation that there is a lack of available evidence which limits the description of such "general and specialist services". As participants in the Transforming Care programme, Care England's members believe that the Care Quality Commission has an important role to play in ensuring that no arbitrary descriptions are applied to services which can meet the needs of individuals, either generally or pursuant to the Transforming Care programme. The assertion that only one model of support should be restricted to one type of accommodation is seriously flawed in our view and will be highly damaging to the sustainability of existing and new services. Ethos, culture, needs and choice are far more important considerations than numbers of beds.	Thank you for your comment. The Guideline Committee agreed on the importance of accommodation as a determinant of health and wellbeing. While there was not strong evidence to support a recommendation of one type of housing over another, or the maximum number of residents to maximise choice, control and wellbeing, the Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
Care England	Short	6	5	5 How does this relate…	Care England strongly endorses reference to the principles established by the Care Act 2014 and the current Care Act Guidance, and believes NICE should encourage everyone, but particularly those responsible for commissioning services to embrace fully all of their actual and target duties under the Care Act and the associated Guidance. As part of that process we strongly believe providers should be more actively engaged by commissioners from an early stage in the planning process. Care England would welcome encouragement on the part of NICE in its Guidance that Government considers further statutory intervention to increase the actual duties on commissioners to ensure adequate provision is made for people with learning disabilities and behaviour that challenges, covering both the strategic commissioning needs in local authority areas as well as the specific needs of individuals seeking services. The point is repeated at lines 18-21 on page 7, where Care England believe that the guidelines should target commissioners in particular as being the agent able to make these changes happen, something which Care England members as providers simply cannot do.	Thank you for your comment. We have referred to the Care Act 2014 when we develop recommendations that develop further on how to achieve the duties set out in the Care Act 2014. The Guideline Committee agree that the role of the lead commissioner is an important one. We have revised the section on Achieving Change to provide greater clarity on the role of the strategic lead commissioner and recommendations on Quality Assurance of services directed to the strategic and individual commissioner.
Care England	Short	7	11	Aims and principles	We believe that the first bullet point should address 'happiness and wellbeing'. This can be something that is overlooked in the wider debates about service model	Thank you for your comment. We have revised this text to include the aims and principles should include helping people • to have a good quality of life • and to achieve physical and mental health and emotional wellbeing.
Care England	Short	7	18	aims and principles	We welcome a variety of services being available to meet individual need – see comments above.	Thank you for your comment and support for this guideline.
Care England	Short	7	8	Aims and principles	We welcome that people should be supported to live where they want but this choice should include residential care as an option where it can offer good quality of care.	Thank you for your comment. The Guideline Committee did not exclude residential care if that was an option that people chose if assessment and care planning show that their needs, including educational needs, cannot be safely met while living at home.
Care England	Short	8	7	1.1.1	We suggest that commissioners should also have in depth knowledge of provision for people with learning disability either through working closely with providers, visiting services or through secondment of providers on to commissioner teams.	Thank you for your comment. We have added reference to knowledge of local services to recommendation 1.1.2.
Care England	Short	9	20	1.1.6	The desire expressed that local authorities develop commissioning strategies rings hollow to many Care England members as many local authorities either do not have an adequate market position statement or their market position statement gives no useful guidance as to the content of a strategy for services for people with learning disabilities. Care England members are more than happy to participate in discussions with local authorities to develop appropriate strategies (for example, those set out in sections 1.1.7 Managing Risk and	Thank you for your comment. The Committee discussed the considerable variation in practice and included reference to the market position statement in recommendation 1.1.8, which says that local and regional plans should be developed that have a single care pathway and point of access for children, young people and adults and that this should be reflected in local authorities' commissioning strategies and key documents such as the Market Position Statement. We hope that the guideline will support changes and improvements in practice in this area.

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					1.1.8 Quality Assurance); however, these are primarily local authorities' functions which they are not fulfilling.	
Care England	short	9	27	1.1.7	Responsibility for the management of risk should also be shared and supported by other statutory agencies such as CQC and the HSE. Reactive responses to incidents that may be notified where agencies are quick to seek to criticise or blame will do little to encourage providers to sustain the support they provide to individuals that may challenge. Too often management of risk is a finger pointing exercise with the provider to blame. It is strongly suggested that these guidelines could form the basis of a more informed mature and a lesson learned approach.	Thank you for your comment. This has been edited to include reference to working with other organisations, to reflect that the people involved will vary depending upon the specific situation and context.
Care England	Short	General		General	Care England is a national representative body for independent providers of care, accommodation and support. This response reflects the range of views of the members of our Learning Disability Group, which incorporates a variety of services of differing sizes, both residential and supported living and includes specialist providers for people with high acuity needs.	Thank you for your comment. We have reviewed and made amendments based on your members' comments, where the Guideline Committee agree.
Care England	Short	General		General	We note the guideline is not specifically addressed to the regulators of these services. It would be helpful to include within the definition of "Practitioners" reference to regulators in respect of the relevant services, including CQC and the HSE as to be effective there needs to be a shared understanding and appreciation that risk is inherent in supporting individuals with behaviour that challenges.	Thank you for your comment. While we do not name regulators as a specific audience, they are included with health and social care and other practitioners, and practitioners in related services, and are actively encouraged to follow our recommendations to help them deliver the highest quality care. In terms of sharing risk, we have revised recommendation 1.1.9 to read that local authorities and clinical commissioning groups need to 'take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person'.
Certitude	Short	1	General	Background	It is not clear why autism is not specifically mentioned as a condition relevant to these guidelines. Whilst it may not cover people who have autism but who do not have a learning disability, the prevalence of people with a learning disability who also have autism who can also present with behaviour which challenges services would suggest it is an important clarification to be made.	Thank you for your comment. The scope of the guideline includes people with autism and who also have a learning disability. After further consideration, the Guideline Committee agreed that this needed greater clarification and have revise the background section to make this clearer.
Certitude	Short	11		1.2.3	In line with our second point above, we feel that the section in the guidelines on the support people need, needs to more explicitly state how support understands and responds to the factors which may trigger people to become distressed/ angry/ anxious and respond in ways that are challenging. Critical areas include the environment (and in particular the sensory environment) as well as the skill set, confidence and continuity of support in relation to communication, structure and routine and active engagement.	Thank you for your comment. We agree that people who work with children, young people and adult with learning disabilities and behaviour that challenges should have the skills and competencies to do so and these relate to the recommendation in section 1.9 on Staff skills and values. Relating to the environment particularly, we have revised recommendation 1.2.21 we have said that in all settings, staff working with children, young people and adults with a learning disability and behaviour that challenges (and their families and carers) should aim to reduce the risk of behaviour that challenges developing by: • identifying health or sensory problems early • providing strategies and interventions to increase support communication and identify health or sensory problems early to reduce their risk of developing behaviour that challenges. Follow the recommendations on psychological and environmental interventions in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).• identifying health or sensory problems early • providing strategies and interventions to increase support communication and identify health or sensory problems early to reduce their risk of developing behaviour that challenges. Follow the recommendations in on psychological and environmental interventions in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.
Certitude	Short	4	General	Background	The descriptors given in the background session do not help understand the causal factors for challenging behaviour only what it looks like. This seems a missed opportunity particularly in relation to service design and delivery to give context on why some people with learning disabilities and autism experience such levels of distress, frustration and / or anxiety that this manifests in behaviour which is challenging for both themselves and those around them. Clarity on when behaviour is a response to something happening and when	Thank you for your comment. NICE guidelines aim not to duplicate guidance which is provided elsewhere. The causes and factors associated with behaviour that challenges are within scope for the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have provided a reference and hyperlink to the relevant sections of the clinical guideline for people who want more detail.

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					and how it becomes a learnt behaviour is a critical starting point for effective service design and delivery.	
Certitude	Short	6	1	How does this relate…	Whilst the guidelines are specifically related to health and social care, the SEND code of practice is important guidance that should have greater prominence in terms of service design and delivery for children and young people. Again, effective service design and delivery is only likely to be achieved through a holistic approach and we therefore suggest the code of practice is included as relevant guidance.	Thank you for your comment. We reference the Children and Families Act 2014 on which the code of practice is based, It explains the duties of local authorities, health bodies, schools and colleges to provide for those with special educational needs under part 3 of the Children and Families Act 2014 and Health, Education and Care plan (EHC), in line with the SEND code of practice.
Certitude	Short	8		1.1.1	The recommendation for a lead commissioner for health, social care *and* education for children, young people and adults with a learning disability is a welcome and really important one. We would suggest it is important to explicitly mention autism as well here.	Thank you for your comment. The scope of the guideline includes people with autism who also have a learning disability. After further consideration, the Guideline Committee agreed that this needed greater clarification and have revised the background section to make this clearer.
Certitude	10	short		1.1.12	We would suggest the inclusion that families and the person themselves are involved in the direct commissioning/ selection of their support provider of their individualised support packages or any other bespoke support which has been developed especially for them.	Thank you for your comment. This recommendation relates to involvement in service-level commissioning rather than co-production of individual support packages. The Guideline Committee agreed strongly that people and their families should be at the centre of planning their support package and this is addressed in detail in section 1.2.
Certitude	9	Short		1.1.7	We suggest that this section makes clear that resources should not prevent developing a multi agency approach to risk management if that is in the person's best interests.	Thank you for your comment. The Guideline Committee considered carefully the resource impact of the recommendations. The committee was also concerned about widespread cuts to services, and hoped that the recommendations of this guideline may strengthen agencies' ability to recommend evidence-based practice and approaches.
Certitude	15	short		1.3.3	We suggest this section makes clear that support to families should be available 24/7.	Thank you for your comment. In the section 1.4 we describe what services should be available in the community to support children, young people and their families. This includes .recommendation 1.4.2 that states that the core functions of community services should be to • giving support and training to families and carers (by following the recommendations on support and interventions for family members or carers in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions) as well as crisis support. We have revised recommendation 1.4.10 to state that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should: • focus on keeping people in their own home • have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems • provide face-to-face support within 4 hours if needed based on initial triage. This is in line with the NHS England 5 year forward plan for adult mental health, 24/7 care. The guideline Committee considered this feasible and necessary to extrapolate this to children and young people as well as adults.
Certitude	19	short		1.4.8	We suggest the timeframe of 18 weeks to access specialist support is too long. Individuals and their families are likely to fall from a difficult to a crisis situation long before this time limit is up and end up requiring more intensive / expensive and longer duration support as a result. An early response and intervention should be triaged and provided within two weeks where appropriate. The triage timescales should be clearly set out.	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed.
Certitude	21	short		1.5.7	This section should include the clinical responsibility and input needed.	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient.
Certitude	22	short		1.6.1	We suggest that not enough emphasis is placed on younger children support services in this section. Whilst CAMHs is an important offer often from the age of 5 onwards. Portage style support in the family home can often provide the most important input in terms of increasing family understanding, confidence and skills in supporting their child in a range of developmental areas which can help reduce / remove the potential causes of challenging behaviour in the longer term.	Thank you for your comment. We have included a new recommendation to make clear that a range of support should be made available for children and young people and their families. This is based on the recommendations in section 1.3 (Support for families and carers).

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Certitude	23	short		1.6.7	We suggest this section should explicitly state where these residential placements are educational and the factors that need to be considered in leaving them.	Thank you for your comment. This recommendation includes residential educational placements for children and young people.
Certitude	25	short		1.7.1	We suggest that the word "sufficient" should be used within this section to describe respite requirements.	Thank you for your comment. This recommendation has been edited accordingly.
Certitude	13	short	11	1.2.11	We suggest Care and Support Plans are developed for children and young people within the context of family life and dynamics and that this should be explicitly stated in section 1.2.11. Support can often be silo'd according to an individuals needs – many families have more than one member with additional needs and understanding what is needed to support the family as whole to thrive is critical.	Thank you for your comment. The Guideline Committee agree that care and support plans should be developed holistically, however we think that this is adequately covered in this recommendation.
Certitude	10	short	12	1.1.8	Reports on the use of restraint AND other restrictive practices	Thank you for your comment. The wording has been edited to 'restrictive interventions' to respond to your comment.
Certitude	30	short	24 onwards		We suggest more clarity is needed in this section about the pathway of support for family members and carers. (Indicators of)Challenging behaviour can start to emerge when a child is under 5 years (Emerson research) and a pathway should already be in place for families – eg: SALT, portage, parent courses (Hanen, Autism etc). families who have children with behavioural support needs will often move in and out of education, health and care support – some may only access 1 or 2 out of the three areas of support. Establishing a clear pathway of where the support is, how and what over the childs life would be helpful.	Thank you for your comment. Section 1.3 sets out early intervention and support for families and carers. NICE is also producing a care pathway to accompany this guideline.
Certitude	13	short	4	1.2.11	We suggest the word "review" is added after develop and deliver. That support plans are dynamic rather than static approaches is important and it's the active review process that enables this.	Thank you for your comment. The Guideline Committee agree that support plans should be reviewed regularly to ensure that they remain appropriate. This recommendation has been revised accordingly.
Certitude	13	short	general	1.6	There is little mention of Education, Health and Care plans in the guidance. Whilst the NICE guidelines focus on heath and care, the reality is that for children and young people the key single document which has most standing is their EHCP which is predominantly an education led process. These guidelines should therefore make more explicit the expectations of health and care in ensuring a joined up approach with education to deliver on the requirements of individual EHCPs. This should include the support that can and should be provided to education to enable children and young people with learning disabilities and / or autism who can also have behaviour which is challenging to remain within mainstream local education settings.	Thank you for your comment. The Guideline Committee agree that Education, Health and Care Plans are a key means of supporting children and young people, however after careful consideration, we think that these issues are adequately covered in this section.
Cheshire and Wirral Partnership NHS Foundation Trust	Full	11	3	1.1.8	The evidence should include: a. 'reports on the use of mechanical restraints' b. Stopping Over-Medication of People (STOMP).	Thank you for your comment. We agree it is helpful to highlight the importance of regularly reviewing medication. We have added a new recommendation 1.2.22 to reflect this. We also reference the recommendations set out in the NICE guidelines - (NICE (2017) Managing medicines for adults receiving social care in the community. NICE guideline NG67) and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Cheshire and Wirral Partnership NHS Foundation Trust	Full	16	15	1.3.3	Talking of 'managed email networks' fails to recognise the range of social media that can be used to facilitate communication. Much of the 'other' forms of social media are more intuitive to use and far more accessible.	Thank you for your comment. We have revised the recommendation to include reference to social media supports

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Cheshire and Wirral Partnership NHS Foundation Trust	Full	17	9	1.3.5	Should we be using the term 'short-breaks' in place of 'respite'	Thank you for your comment. Following stakeholder feedback we have used the term 'short breaks' in the guideline as the preferred term and included a definition in the terms used section to make clear we mean short breaks for children, adults and young people.
Cheshire and Wirral Partnership NHS Foundation Trust	Full	20	4	1.4.8	'People should never wait more than 18 weeks'. The length of time a person waits should be defined by a process of triaging and a determination of risk. All services should have a triage system in place. This system should clearly describe the relationship between assessed risk, response time and expected intervention type.	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems and to provide a face to face response within 4 hours if that is what is needed. We have revised Recommendation 1.4.9 which now reads that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support.
Cheshire and Wirral Partnership NHS Foundation Trust	Full	20	8	1.4.9	The document states: 'have sufficient capacity to respond within 24 hours' This should be again qualified by an assessment of risk as per comment 6 above. This statement should also qualify: a. Iif this '1 hour response' is 24 hours per day. b. What is meant by response – is this a telephone call, face-to-face, etc.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Cheshire and Wirral Partnership NHS Foundation Trust	Full	25	7	1.6.9	It states, 'The lead commissioner should ensure a plan is developed….' The development of this plan must involve representation from specialist ADULT services if the young person is aged over 16. This point again highlights the fact that there is no section on 'Transition'.	Thank you for your comment. The lead commissioner's remit should cover both children's and adults' services (see recommendation 1.1.1) to ensure smooth transitions (see recommendation 1.1.2).
Cheshire and Wirral Partnership NHS Foundation Trust	Full	26	14	1.8.1	People should only be admitted to an assessment and treatment service if: a. Their needs can only be assessed in an inpatient setting, and, or; b. Their needs can only be treated in a hospital setting because the risk of treating them in the community would place than at very significant risk. c. Points (a) and (b) above have been reviewed as part of the Care and Treatment Review. At the point of admission there should be a clear commitment to ensuring there is or will be a discharge pathway available to the person within a period of 12 weeks – the period of time available to assess someone under s2 of the Mental Health Act.	Thank you for your comment. After careful consideration, we think that these issues are adequately covered in recommendations 1.8.1 and 1.8.2. The Guideline Committee also recommend that discharge planning begins at admission to the inpatient setting (please see recommendation 1.8.9).
Cheshire and Wirral Partnership NHS Foundation Trust	Full	9	16	1.1.4	The term 'contingency fund' needs further elaboration. What is it? How is it structured? Who is accountable for its development? Who is operationally responsible for it? Is it written into the s75 agreement?	Thank you for your comment. The wording of this recommendation reflects the evidence presented by the expert witness. This is discussed in more detail in the full guideline, section 3.7 'Evidence to recommendations'. We have added a definition in the 'terms used' section. The operationalisation of the fund has not been defined to allow for flexibility in local level implementation.
Cheshire and Wirral Partnership NHS	Full	General		General	There is insufficient attention given to transition from child to adult services. The document should have a section devoted to this. There should be some very clear statements linked to the effective commissioning and delivery of safe and sustainable transition services.	Thank you for your comment. The transition from children to adult services is the subject of another guideline (Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43) and out of scope for this guideline.

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Foundation Trust					Attention should be given to describing person centred clinical and systemic outcomes that an effective service should realise. The section on Transitions into Adult Services should include: a. The designated lead commissioner for child and adult services must be responsible for the multi-agency transition strategy and its implementation. b. The transition strategy is managed by a transition partnership board. The multi-agency transition strategy appoints a Transition Coordinator to take the operational lead on strategy implementation	The Guideline Committee did consider that the role of the lead commissioner, who would have oversight of both children's and adult services and take a whole life approach to planning for services would ensure that people experienced minimal transition between services.
Cheshire and Wirral Partnership NHS Foundation Trust	Full	General		general	Should the tables be numbered and have a title. For example – Table 1. Showing……..	Thank you for your comment. We have kept the format of the tables to be consistent with other guidelines and the NICE manual (Developing NICE guidelines: the manual. Process and methods PMG20).
Cheshire and Wirral Partnership NHS Foundation Trust	Full	General		general	Throughout the document 'expert-opinion' is referenced. Would it be better practice to gather expert opinion from a 'pool' of experts and using methodology such as Delphi panels?	Thank you for your comment. We are unclear about the meaning of this suggestion, as we have not used the term expert-opinion. We have used the term "experts by experience" to mean people with lived experience of using services, either themselves or as a family carer and who can contribute to the quality monitoring and service design of services for people with learning disabilities and behaviour that challenges. In the longer version of the guideline we have used the term expert witness to describe a guest who can describe current good practice as a professional or expert by experience to provide evidence where research evidence was lacking or weak. The Guideline Committee itself comprises of experts by experience as well as professionals, academics and other practitioners. They interpret the research evidence or evidence from expert witnesses to make recommendations in agreement, using "modified" consensus methods. Elements of formal and informal consensus methods, methods are used to consider the strength of evidence and recommendations.
College of Mental Health Pharmacy	Short	11	28-29	1.2	Enabling person-centred care Involving people and their family members and carers should also involve the medicines and the types of healthcare available	Thank you for your comment. We reference the recommendations set out in the NICE guidelines - (Managing medicines for adults receiving social care in the community. NICE guideline NG67) for adults receiving social care in the community and The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for people with a learning disability and behaviour that challenges using inpatient services..
College of Mental Health Pharmacy	Short	15	1-9	1.3.1	Support for families and carers Included in the people mentioned should be access to specialist pharmacist advice about the medicines prescribed and whether they need to be on all the medicines	Thank you for your comment. We have revised recommendation 1.3.1 to remove terms related to a profession title and only included references to specialist services that are in line with the evidence-based interventions in the clinical guideline, (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have added an additional statement in the 'Care and support planning' section - 1.2.22, to emphasise the need to follow recommendations in the NICE guideline (NICE (2017) Managing medicines for adults receiving social care in the community. NICE guideline NG67) and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We also have included a statement about the need to ensure medications are reviewed regularly in line with NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
College of Mental	Short	16	7-19	1.3.5	The named worker in the community learning disability team should make regular offers of support to understand this information from the first point of	Thank you for your comment. We have carefully considered your request and have decided to keep the focus of the recommendation on helping people understand information rather than offering support as

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Health Pharmacy					contact onwards. Advise family members or carers about their right to, and explain how to get: This should include good advice about the medicines including the STOMP programme	such. The recommendation states that help should be provided 'from first contact onwards' which implies that help will be ongoing. We have added an additional statement (1.2.22) to emphasise the need to follow recommendations in the NICE guidelines - (Managing medicines for adults receiving social care in the community. NICE guideline NG67) for adults receiving social care in the community and The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for people with a learning disability and behaviour that challenges using inpatient services. Recommendation 1.2.22 also includes a statement about the need to ensure medications are reviewed regularly in line with the clinical guideline mentioned above.
College of Mental Health Pharmacy	Short	17	18-30	1.4. 3	Please include Specialist Pharmacists who will be able to assist the carers with decisions about the medicines and STOMP	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
College of Mental Health Pharmacy	Short	7	1		1. People have the right to be involved in discussions and make informed decisions about their care, as described in your care. However included in care should be a right to have a say in their drug treatment and the access to healthcare	Thank you for your comment. The **Your Care** document is a standard NICE document, which also covers healthcare and treatment. We have added a new recommendation 1.2.22 to say that: For people taking medicines: • follow recommendations in NICE's guidelines on managing medicines for adults receiving social care in the community and • if the reason for the medicine relates to the person's behaviour or mental health, ensure it is reviewed regularly in line with recommendations on medication in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions and mental health problems in people with learning disabilities: prevention, assessment and management. These guidelines include recommendation on how to include people in decisions and managing their own medicines. Recommendation 1.3.1 also states that people should be supported to meet their needs, including their physical and mental health needs. Recommendation 1.4.3 includes a reference to supporting people to access specialist care, including for their physical and mental health needs.
College of Mental Health Pharmacy	Short	General		General	The scope excludes all healthcare issues because of the availability of guidance about healthcare elsewhere. However NG11 evaluates healthcare but provides very little to guide commissioners about how good social care also includes access to all aspects of healthcare	Thank you for your comment. The Guideline Committee agree that access to healthcare was important. The research literature suggested that some people were not able to access healthcare when they were living in the community supported by social care services. The Guideline Committee considered this evidence and revised the 'aims and principles' section to include that services should 'support people to have good physical and mental health and emotional wellbeing'. In addition the Guideline Committee revised the recommendation in 1.2.21 that staff in all settings 'should aim to reduce the risk of behaviour that challenges by identifying health or sensory problems early'. The Guideline Committee also considered transitioning in recommendation 1.6.4 and revised this to say that services should support smooth transitions between services in line with organising effective care in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
College of Mental Health Pharmacy	Short	General		General	One would expect as a gold standard that all provider organisations have signed up to the STOMP programme –stopping the overuse of medication for people with a learning disability, autism or both.	Thank you for your comment. We agree it is helpful to highlight the importance of regularly reviewing medication. This is covered in recommendation 1.2.22. We reference the recommendations set out in the NICE guidelines - (NICE (2017) Managing medicines for adults receiving social care in the community. NICE guideline NG67) for adults receiving social care in the community and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE

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						guideline NG11) for people with a learning disability and behaviour that challenges using inpatient services.
Darlington Borough Council	Short	12		1.2.16	Reference 1.2.16 can a local authority offer a personal health budget? Darlington Borough Council	Thank you for your comment. We have revised recommendation 1.2.19 to read that local authorities and clinical commissioning groups need to 'ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences'. Think about using integrated personal commissioning where it is available to support this.
Darlington Borough Council	Short	15		1.3.3	- an explicit reference to Facebook may help?	Thank you for your comment. We have revised the recommendation to include reference to social media supports
Darlington Borough Council	Short	21		1.5.5	In 1.5.5 - where did the figure 3 come from?	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. It was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The cost effectiveness research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another or the optimum or maximum number of residents that could be specified that would be suitable for everyone, for this reason the reference to a specific number has been deleted. The Guideline Committee interpreted the available research evidence that congregating people together based on their behaviour that challenges and not based on their preferences or compatibility with other residents achieved worse outcomes, and cost effectiveness evidence that it was no more cost effective to group more than 6 people together. Evidence from expert witnesses together with their practice and experiential knowledge indicated that small numbers were more like an ordinary home for most people where people had a choice over who they lived with. The Guideline Committee agree that there was a lack of information on the most cost effective forms of accommodation and have developed a research recommendation to address this as a priority for future research.
Darlington Borough Council	Short	21		1.5.7	1.5.7- "Responsible Commissioner" is a specific health role. Not used in the Local Authority. Can this be clarified?	Thank you for your comment. We have revised this recommendation to be directed to: local authorities, clinical commissioning groups and commissioners
Darlington Borough Council	Short	22		1.5.8	1.5.8 - should this include employment/pre- employment as an option	Thank you for your comment. We have added this as you suggested (now recommendation 1.2.23).
Darlington Borough Council	Short	27		1.9	- perhaps needs a better description than showing "that they care" caring can manifest itself in a number of ways. Better words might include respect, value, support for citizenship, decision making rather than care.	Thank you for your comment. We agree that there are different ways of expressing caring that are important to people, and we have included examples of this in this recommendation, for example 'understanding and respecting the person's human rights, faith, culture, identity and values'.
Darlington Borough Council	Short	6		How does this relate…	On Page 6 should the Mental Health Act be identified as relevant legislation?	Thank you for your comment. We have added the Mental Health Act 1983 to the list of relevant legislation and guidance.
Darlington Borough Council	Short	7		Aims and principles	Rather than using the word "care" could the word "support" be added e.g. care and support in line with the Care Act. Local self advocates in Darlington see care as something given rather than support which is seen as more person centred e.g. Pg. 7 could read person centred care and support.	Thank you for your comment. We have revised the text based on your suggestions to read care and support to be in line with the Care Act.
Darlington Borough Council	Short	Gene ral		general	Overall the Local Authority welcomes the guidelines. They offer a positive framework within which the support needs and individual aspirations of people with a learning disability with behaviour that challenges can be met.	Thank you for your comment and support for this guideline.

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Darlington Borough Council	Short	General		general	The Local Authority welcomes the option of developing a local infrastructure that works for its citizens.	Thank you for your comment and support for this guideline.
Darlington Borough Council	Short	General		general	As a Local Authority we have undertaken a considerable amount of work with people with a learning disability and their families and carers in relation to the language used when talking about disabled people. Indeed locally self advocates have asked that we use the term learning impairment rather than learning disability.	Thank you for your comment and suggestion. We acknowledge that there are different terms used, over time and geographical area. To avoid confusion, we have used the term that is currently used in the literature and that has been used in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). In future, different terms may be used that reflect the current knowledge, understanding and preferred terms.
Darlington Borough Council	Short	General		general	In relation to the title of the Guidance. Could it be changed to: "Children, young people and adults with a learning disability and behaviour that challenges how they are supported: service design and delivery. This is in line with "people first" thinking.	Thank you for your comment. We have carefully considered your request and have decided to retain the title to be consistent with the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) and more accurately reflects the recommendations around strategic planning of services and how services should work together as well as how they should support people with learning disabilities and behaviour that challenges.
Darlington Borough Council	Short	General		general	Can there be some consistency through the document. For example people with a learning disability rather than learning disabilities. We think it's a singular thing i.e. someone has a learning disability not learning disabilities and it seems less of a burden.	Thank you for your comment. We agree this needs to be consistent and we have revised the text based on your suggestion.
Darlington Borough Council	Short	General		general	Within adult social care words like "severe, moderate and borderline" are no longer used instead the behaviour itself is described rather than the label of "severe" given without context.	Thank you for your comment. We agree it is important to use the right words when describing behaviour that challenges. In this case we have not used the words severe, moderate and borderline to describe behaviour, but in describing the degree of learning disability consistent with the definition used in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). In the clinical guideline a learning disability is defined as meeting 3 core criteria: • lower intellectual ability (usually an IQ of less than 70) • significant impairment of social or adaptive functioning • onset in childhood. A person's learning disability may be mild, moderate, severe or profound in severity. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.
Darlington Borough Council	Short	General		general	Local self advocates have questioned the use of the word respite to describe an activity or action. People prefer to use the term "short break".	Thank you for your comment. We agree that the term "respite" is not one preferred by many people. We have revised recommendations that refer to respite to be short breaks for children, young people and adults and defined the term "short breaks" to mean for everyone not just for children, as the term short-breaks is more commonly used.
Darlington Borough Council	Short	General		general	There is no reference to protocols for placing people out-of-area. Agreed protocols would ensure local services were prepared. This would include alerting a local authority or CCG of a potential placement being made in their area. This would also help the placing Authority understand any local issues.	Thank you for your comment. We did not find research evidence that agreed protocols led to better outcomes. We hope that if the recommendations are implemented as intended, people would have access to services that they need in their local area, and reduce the need for people to be placed away from home.
Darlington Borough Council	general	General		general	There is no reference to "Citizenship" in the document. Which is after all what we all strive for? A focus on citizenship and what it means offers a useful framework to both measure how people are living their lives and how they are supported.	Thank you for your comment. We did not find research evidence from people's views and experiences that "citizenship" was a commonly held framework to understand what most people want to achieve in their lives. Instead, we have focused on self-defined goals, that people should be able to choose the life that they want to live.
Darlington Borough Council	Short	General	general	general	Re "Assessments of vulnerability" again self advocates have questioned the use of words like vulnerable to describe people rather than setting out what particularly makes someone vulnerable.	Thank you for your comment. We agree language is very important representation of people's identity and lived experiences. In this recommendation we have used language that is understood by police and liaison and diversion teams to describe these specific assessments to avoid confusion.
Darlington Borough Council	Short	General	general	general	In short this is the opportunity to use language in a positive way to begin to shape culture around people with a learning disability and behaviour that challenges how they are supported.	Thank you for your comment. We agree language is a very important representation of people's identity and lived experiences. We have revised terms wherever possible, and retained terms only when it would be a barrier to implementation of the recommendations because of confusion over the terms more commonly used.

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Darlington Borough Council	Short	General	general	1.2.8	The access to and use of advocacy should be strengthened. Perhaps even consider access to independent advocacy as a default position.	Thank you for your comment. This has been revised as you suggested and recommendation 1.2.8 now reads: Local authorities must offer independent advocacy as described in the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 2007. In addition, think about offering it whenever it is wanted or needed by a person with a learning disability and behaviour that challenges.
Darlington Borough Council	Short	General	general	general	More emphasis on the use of Personal Health Budgets/Direct Payments. The Local Authority is not in a position to drive the take up and delivery of Personal Health Budgets.	Thank you for your comment. We have revised recommendation 1.2.19 to include the commissioners' role in making sure that funding arrangements are available, including direct payments, personal budgets or individual service funds and in recommendation 1.2.20 that people should be helped to access these. The recommendations on accessing personal budgets was adapted from the NICE guideline on older people with social care needs and multiple long-term conditions, which recommended that people were supported in the use of personal budgets. The Guideline Committee extrapolated these recommendations for older people and their carers to this population. This was further supported by the expert witness testimony from the Devon case study which consisted of a commissioner of services, a charity that supports people with learning disabilities accessing services and a mother of a young women with learning disabilities who had displayed behaviour that challenged services in the past. They said that they found that person-centred care included the use of Personal Health Budget (PHB) or by using the PHB as an Individual Service Fund (ISF). This meant they could start with a 'blank slate' and not have to compromise too much based on what services there were already available. They said it was a way of people having power and control over their money and life without the overall responsibility which can sometimes involve large sums of money and complicated legal employment responsibilities. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Darlington Borough Council	Short	General	general	general	Person centred care and person centred support are different. The Guidance should make reference to person centred support. There is a marked difference between care and support. Social care focus is more on support.	Thank you for your comment. We have revised our terms used to be "care and support" consistently, to be in line with the Care Act 2014 and reflect local authorities' legal duties to promote integrated health and social care when this promotes wellbeing.
Darlington Borough Council	Short	General	general	general	There should be more included on the importance of relationships and their value to individuals.	Thank you for your comment. We have revised recommendation 1.2.23 to say 'Ensure that children, young people and adults know about and are able to use services to support their health and wellbeing. Services (should) help people to make and maintain friends, relationships and social networks in their community and take part in community activities.'
Darlington Borough Council	Short	General	general	general	We welcome the promotion of the use of Individual Service Funds; however there is no reference to Individual Service Design as a model for developing person centred support.	Thank you for your comment. We did not find research evidence on individual service design as an approach to designing services, however the Guideline Committee felt that it was important to reflect the same ethos in enabling people to live a life that they choose, to maximise choice and control and to have care and support built around the person instead of one size fits all.
Darlington Borough Council	general	General	general	general	A focus on individual service design and a bespoke approach will support the development of support that is individual rather than a focus on what exists.	Thank you for your comment. The Guideline Committee agree that services should be designed around the person and it is the intention of the recommendations that they reflect that.
Department for Education	Short	23	10-13	1.6.5	We're concerned with this text as it doesn't acknowledge the role that parental preference can play in deciding where a child or young person may be placed. Parents, for example, may express a preference for a place in a residential special school or college on the child's education, health and care plan. The local authority must then fulfil that request unless specific criteria apply – that the provision would be unsuitable for the young person's needs, incompatible with the efficient education of others or an inefficient use of the local authority's resources. Adding a line that noted the potential for this exception would probably circumvent this.	Thank you for your comment. We agree that the previous wording was not clear that Local Authorities have a conditional duty to meet parental choice in line with the Children and Families Act 2014. We have revised this recommendation to say that the lead commissioner, service providers and practitioners should make an offer of a residential placement for children only if: • assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted; or • This is the residential placement that has been chosen by the families in their Education, Care and Health plan, and the residential placement can meet their needs, in line with the Children and Families Act 2014.

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Department for Education	Short	24	7-10	1.6.9	Again, this doesn't take into account the potential role of parental preference. For some parents, a residential placement is a positive choice. Often, the process of accessing a residential placement can be an acrimonious one, as LAs can sometimes be resistant to placing children in these more expensive placements (see Dame Christine Lenehan's recent review of residential special schools and colleges). Families feel they have to fight to access the placements, and often do not trust the LA as a result. They may therefore resent the LA immediately beginning to plan to end the placement.	We agree that it was not clear that Local Authorities have a conditional duty to meet parental choice in line with the Children and Families Act 2014. We have revised this recommendation to say that the lead commissioner, service providers and practitioners should make an offer of a residential placement for children only if: • assessment and care planning show that their needs (including their educational needs) cannot be met while they are living at home, and all alternatives to residential care have been considered and exhausted; or • this is the residential placement that has been chosen by the families in their Education, Care and Health plan, and the residential placement can meet their needs, in line with the Children and Families Act 2014.
Department of Health	Short	General	general		No comments.	Thank you for your comment.
Dimensions	Short	10	1-25	1.1.8-1.1.11	It would be important to include outcomes that align more directly with the aims of the guidance. For example, information on the actual occurrence of behaviour that challenges (across all relevant dimensions: frequency, duration, severity). It would also be worth gathering information on known risk factors for behaviour that challenges, many of which are already referenced in NICE's clinical guideline on challenging behaviour and learning disabilities: prevention and interventions (2015) – for example, rates of skill acquisition. We would also like to suggest existing social care standards such as Reach and DUQ	Thank you for your comment. The aim of this guideline is to complement rather than replicate the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Dimensions	Short	10	27-29	1.1.10	We welcome the guidance on employing experts by experience and believe it is essential that this input can operate outside of professional control to ensure the value of experience is truly taken on board.	Thank you for your comment, and for your support for the guideline.
Dimensions	Short	11	6	1.2.1	We agree that staff must understand what people want from their lives, not just services. Organisational values and principles can support this. At Dimensions we integrate our organisational values into the person centred planning process so that thinking about what people want from life is embedded in our care and support planning.	Thank you for your comment and support for the recommendation.
Dimensions	Short	12	10-12	1.2.7	Everyone with a learning disability and behaviour that challenges should be assessed by a specialist Speech and Language Therapist and communication needs should be clearly expressed in the support plan with a scheduled review. Any training needs around communication to enable family and support staff to understand and be understood by the person should be written into the support plan and adequately funded.	Thank you for your comment. We have revised this recommendation to include reference to the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of people, carers and families with a disability, impairment or sensory loss using health and social care services. We say in recommendation 1.3.5 that training for families and carers needs to be in line with recommendations 1.7.1 and 1.7.2 in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Dimensions	Short	12	20	1.2.8	Independent advocates should also have skills and experience working with families.	Thank you for your comment. Recommendation 1.2.9 reads that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in working with specialist learning disability services.
Dimensions	Short	12	29	1.2.10	Recognition of unpaid people must consider the need to pay travel costs and other care costs (for example for additional dependents) to enable full participation. Dimensions	Thank you for your comment. The committee were clear that the expertise of all members of an individuals' support network should be recognised. However it was not possible to include reference to the costs of this in this recommendation as we did not have evidence about the relative costs and benefits that would enable us to justify additional expenditure by local areas. Specific economic analyses were not conducted in relation to this recommendation. We looked for economic evidence if it was there

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						and considered them with the Guideline Committee . If there were no economic evidence, then the Committee had their own discussion which informed the recommendations
Dimensions	Short	12	7-9	1.2.6	Staff working with people with learning disabilities should also establish and record the communication needs of their families.	Thank you for your comment. We have revised this recommendation to include families. We also say that this activity should be in line with the Accessible Information Standard.
Dimensions	Short	13	12-17	1.2.12	The behaviour support plan should be developed in partnership with the educational setting where the person attends school or college.	Thank you for your comment. NICE guidelines aim not to duplicate guidance which is provided elsewhere. The development of behaviour support plans are covered in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Dimensions	Short	13	5	1.2.11	A care plan should meet someone's ambitions, as well as their needs and preferences. It should also respond to their friendships and connections in life.	Thank you for your comment. This is covered in recommendation 1.2.14 which states "adopts a whole life approach that covers what they want to achieve in both the short- and long-term".
Dimensions	Short	14	21	1.2.17	Local authorities should support people to plan the initial use of their budget as many people and families lack confidence in doing this. Dimensions	Thank you for your comment. We have revised this recommendation to give more examples of how people can be supported including: • telling them how much money is available and how much control they have over how the money is spent • giving them and their families and carers information about different ways of managing their budgets, and how these may affect their carer • supporting them to try out different mechanisms for managing their budget • offering information, advice and support to people who pay for or arrange their own care and support, as well as to those whose care and support is publicly funded • offering information about benefits entitlement • ensuring that carers' needs are taken fully into account
Dimensions	Short	19	7-8	1.4.8	We welcome the use of specific targets in the guidance.	Thank you for your comment and your support for the guideline.
Dimensions	Short	21	10-11	1.5.6	We are concerned that the guidance only places an upper limit on people living in shared accommodation and does not specify an upper limit to the number of people who can live in self-contained units on a single site. It is not unusual in current commissioning to see 10 people living on one site and up to 20-25 people. We recommend that the guidance discourages having a large number of people living on one site, even in self-contained units, in line with the specifications made by Transforming Care and Building the Right Support. At present, Transforming Care guidance recommends no more than 6 people.	Thank you for your comment. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. It was more important that people had a choice over where they lived, that the type of accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. The Guideline Committee interpreted this evidence and evidence from the expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more like an ordinary home for most people. The Guideline Committee favoured accommodation which offered security of tenure and a split between supported service provision and accommodation.
Dimensions	Short	27	1	1.8.10	We question why the Care Programme Approach is promoted in the guidelines, as opposed to the Care and Treatment Review framework and guidance.	Thank you for your comment. We have added reference to the Care and Treatment Review process to this guideline. The recommendation wording is deliberately weak "think about" as there was no firm evidence that one review framework approach was more effective or preferred over another.
Dimensions	Short	27	22	1.9.1	Transforming the professional language that is used by staff is also important. Using straightforward words and messages helps to engage with people and families and ensure that they feel meaningfully involved in their care.	Thank you for your comment. We did not find evidence from research evidence of people's views and experiences that the kind of language used was a barrier to good care, but many of the recommendations include working with the person and their families effectively and in a meaningful way. The Guideline Committee discussed that people's communication needs could be a barrier to good care and this was considered in the Equality Impact Assessment. The Accessible information Standard was added to recommendation 1.2.6 to make sure the person and their families' communication needs are met and also recorded and shared with people who work with them.
Dimensions	Short	7	13-14	Aims and principles	Skilling in Active Support and Positive Behaviour support will needed to achieve this with people – this should be emphasised in section 1.9 (page 27) of the guidance.	Thank you for your comment. The Aims and Principles section has been further developed to include more of the aims that are important to people and their families. Section 1.9 on the skills and competencies that staff need for working with people with learning disabilities and behaviour that challenges. The recommendations reference and hyperlink to the Positive behaviour support

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						competence framework . There was some debate in the Guideline Committee as to whether "Active Support", was an approach or an intervention, and it was decided specific interventions, such as Active Support is in scope of the clinical guidelines, NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Dimensions	Short	9	27-31	1.1.7	Risk management plans should closely involve the person and their family and should be directly linked to support and care planning.	Thank you for your comment. We have revised recommendation 1.4.8 to include assessments of both need and risk. Specific risk assessments are referenced in section 1.5.7 on risk assessment in the clinical guideline NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have referenced the clinical guideline where appropriate.
Dimensions	Short	General		General	Overall the recommendations show a good level of understanding of good support for people with learning disabilities and behaviour that challenges and we agree with the underlying principles. The guidance seems like a natural progression from the Transforming Care agenda.	Thank you for your comment and support for the guideline.
Dimensions	Short	General		General	Greater clarity could be given in referencing the local authority and the lead commissioner responsibilities. At certain points, reference is made to 'the local authority should', but it is not clear whether this is in fact the responsibility of the lead commissioner operating within that authority.	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Down's Heart Group	Full	12		1.2.1	Support plans need to be informed by regular input and feedback from service users – so choice and control element needs to consider mechanisms to enable support and promote this – evaluations of regular surveys to inform service review and development. Allows for changes in needs/wishes.	Thank you for your comment. The Guideline Committee agree that support plans should be reviewed regularly to ensure that they remain appropriate. This recommendation has been revised accordingly.
Down's Heart Group	Full	13		1.2.8	Advocacy needs supportive explanation and how to change your advocate or seek help from a nominated advocacy charity	Thank you for your comment. The specifics of how to provide advocacy was out of scope for this guideline.
Down's Heart Group	Full	13		1.2.9	Named worker is a nice idea – people move on how will that be maintained over time?	Thank you for your comment. We have revised the recommendation to say that care and support needs to be coordinated over the long term.
Down's Heart Group	Full	15		1.2.16	Say what financial guidance will be available how this will be kept current independent and impartial.	Thank you for your comment. The topic of financial guidance was out of scope for this guideline.
Down's Heart Group	Full	17		1.4.1	How will different specialist support teams work together – not a good track record here – provide a named team and individual case worker?	Thank you for your comment. Recommendation 1.2.10 - Coordinating care and support covers this. The recommendation states that a single practitioner or 'named worker' should coordinate a person's care based on their needs and over the long term. Recommendation 1.2.12 says that 'the local authority, clinical commissioning group, service providers and others should engage with the single practitioner, keeping them informed and involved in decision making'.
Down's Heart Group	Full	21	All	1.5	Guidelines should include minimum and maximum expectations regarding living support re distance from family, standard of accommodation, any special adjustments/equipment/support.	Thank you for your comment. The Guideline Committee agreed on the importance of accommodation as a determinant of health and wellbeing. While there was not strong evidence to support recommendation of one type of housing over another, or to recommend minimum and maximum standards, The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
Down's Heart Group	Full	25	All	1.7	What if the respite care offered in the local area isn't suitable is there support outside of the local area – are there limits on the amount and type of respite care per individual case if so say so if not say so.	Thank you for your comment. The guideline emphasises the need to develop local capacity (see for example the 'Aims and Principles' section) and we hope that the guideline will inform commissioning and service planning to ensure this.
East London NHS Foundation Trust	Short	10	2-15	1.1.8	It might be beneficial to make specific mention of Quality of Life measures.	Thank you for your comment. This recommendation has been updated to include reference to quality of life ratings, as suggested.

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East London NHS Foundation Trust	Short	11	14-29	1.2.4	We wondered whether the explicit reference to involving people in decisions about restrictive care (physical intervention and behavioural approaches) would be an important addition to the guidance. For example, people with psychosis can make advance decisions regarding their treatment when they become unwell- more explicit reference to such a practice may be useful for people with a diagnosis of Learning Disability who have capacity to make decisions about their care when presenting challenging behaviours.	Thank you for your comment. We note that this is in line with the Mental Health Act 1983 We agree it is useful to highlight how the guideline relates to other guidance and legislation. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation.
East London NHS Foundation Trust	Short	12	10-12	1.2.7	We wondered why the guidance refers to "specialists in communication" and not specifically refer to Speech and Language Therapists. If NICE is not recommending staff have access to SLTs when needed, then who is it NICE is referring to? Question 1: This could be challenging to implement and ensure staff have access to consistently good recommendations as a vague term such as "specialists in communication" leaves it open to this being provided by those without the necessary qualifications. Further clarification is requested with regards to the term access to? Is this describing long term access or access for assessment and recommendation on a one-off occasion only?	Thank you for your comment. We have revised the recommendation to refer specifically to speech and language therapy, rather than 'specialists in communication'. We hope this also addresses your point about implementation. We have phrased this recommendation in terms of people having access when they need it – this could encompass either short or long term access. This is in recognition of the importance of supporting communication as a means of preventing and addressing behaviour that challenges.
East London NHS Foundation Trust	short	12	22-29	1.2.9-1.2.10	Question 1: The draft guideline sets out that all individuals with challenging behaviour have a 'named worker' – in practical terms this would be too many clients for many services to manage. We do not disagree with the guideline – just that the current resources to meet this guideline are out of step with the ever increasing need that has arisen in the context of increased social deprivation. Question 3: It may be helpful for there to be both Good Practice standards (everyone to have a named worker) and minimum standards that absolutely must be adhered to with some consideration of risk/need to help identify who to prioritise for coordination.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. We have recommended that the named practitioner is one of the people already working with the person – not a new member of staff. This means the resource impact will be less. We have also revised the recommendation to make it clearer about how local authorities, clinical commissioning groups and service providers need to work in partnership to coordinate care and support.
East London NHS Foundation Trust	Short	18	15-20	1.4.5	Perhaps there should be an emphasis on joint working for people who are already known to the LD teams to avoid transition of care causing unnecessary delays in support/removal of known support system at a time of crisis. Question 1: This recommendation would be challenging to implement on the particular basis that there is currently no community forensic service for people with LD locally. Question 2: There would be a significant cost implication to delivering on this recommendation as this would mean a team would need to be commissioned locally to do community LD forensic work. If consultation was provided by such a team but the implementation of recommendations and follow-up expected to be done by the local community LD team – there would also be significant cost implications for the LD team, which may prevent this guideline from being implemented.	Thank you for your comment. We agree that community learning disability teams (CLDTs) and forensic services should work together. This could be achieved by employing practitioners within the CLDT or by developing close links with practitioners in other relevant services. We hope that the recommendations, if implemented, will encourage greater collaboration between services to deliver serviceS in line with the good practice in this guideline.
East London NHS Foundation Trust	Short	19	13-16	1.4.9	Re 'out of hours helpline' – what would you expect this to cover? Would this be a way to access emergency respite or advice around risk management during a crisis? Depending on the remit it could have significant cost implications. Some Good Practice examples would be helpful.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or inpatient admission due to the lack of available specialist support in the community. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.

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						The resource impact report that considers the costs and benefits of these recommendations, identified providing intensive support in a crisis (after the initial telephone triage assessment) as an area that would likely incur additional costs. However, the evidence suggested that people from a wide range of groups were at more risk of being placed out of area, especially people that had more complex support needs, and providing intensive support during a crisis will reduce the likelihood of people being placed out of their local area.
East London NHS Foundation Trust	Short	19	17	1.4.9	Re 'capacity to provide a response within 1 hour' – what is the scope of the response being referred to? Question 1: This is too vague a recommendation and will make it hard to implement consistently across England. It could potentially include options such as an appointment being arrange for the same day or 3 weeks later – both could be interpreted as 'responses'. Question 2: Implementing this recommendation (depending on the scope of 'response') could have very significant cost implications. Question 3: It would be very helpful to have some good practice examples of how other teams are managing this. – Whether the teams are embedded in the main team, if people have duty systems, the skills and training that the responders have, the range of responses that are typically provided, whether there is a separate budget…	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system. The resource impact report that considers the costs and benefits of these recommendations, identified providing intensive support in a crisis (after the initial telephone triage assessment) as an area that would likely incur additional costs. However, the evidence suggested that people from a wide range of groups were at more risk of being placed out of area, especially people that had more complex support needs, and providing intensive support during a crisis will reduce the likelihood of people being placed out of their local area. In addition, We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or inpatient admission due to the lack of available specialist support in the community. We have emphasised what the response is to achieve, rather than the specific configurations of staff to allow for flexibility in local implementation. It is not NICE house style to provide practice examples within the guideline. However, NICE do produce resources to support implementation.
East London NHS Foundation Trust	short	19	5-8	1.4.8	It would be helpful to set out a clear statement as to what constitutes 'treatment' in relation to interventions for behaviours that challenge to help teams work consistently towards the 18 week target. A full functional assessment may take time from first contact, within the spirit of the guidance links are made to more formal functional assessments which may (should) include the following six stages; A clear description of the behaviours of concern (including classes or sequences of behaviour that occur together). Synthesizing data to create an overview of a person's skills and needs. The identification of the events, times, and situations that predict when the behaviour will and will not occur across the person's full range of typical daily routines. Identification of the consequences that maintain the behaviour (that is, the purposes or functions that the behaviour appears to serve for the person). The development of one or more summary statements or hypotheses that describe specific behaviours, the situations in which it occurs, and the consequences that may maintain it. The collection of direct observational data that support the summary statements that have been developed. Yet none of these may be described as 'starting a treatment' as it is in the assessment stage still. Further description of what the expectation of the "treatment phase" consists of would ensure local teams could adapt their screening or triage procedures to match best practice. And conversely, it is possible that recommendations could be made at a very early stage about how to respond to behaviours that challenge whilst the case is not yet allocated to a clinician for ongoing work. Technically this could fulfil the requirements of 'receiving advice about how to manage the condition' but may not be in the	Thank you for your comment. We agree that families should access the right support at the right time. We have revised recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disabilities and behaviour that challenges, and specialist skills in mental health problems and to provide a face-to-face response within 4 hours if that is what is needed. We have revised Recommendation 1.4.9 which now reads that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support.

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					spirit of the guidance. Given the nature of functional assessment process it may be helpful to be more specific.	
East London NHS Foundation Trust	short	21	10-11	1.5.5	Unclear about the research base for houses of 4 people – please can you include this. Question 1: Many shared houses have much more than three residents and there is a continued risk that providers are opening homes with many residents and shared facilities as these are cheaper to run. This risks institutionalisation within the community. Yet there are also poor services for 1 bed flats and good services that are 8 beds. Yet these large organisations continue to prosper even when the local authority declines to place people there due to their concerns as OOB authorities still do. There seems to be little teeth to have this guideline implemented. Could there be a recommendation to monitor providers that have larger group homes more frequently to ensure that they are continuing to meet the needs of people and promote independence.	Thank you for your comment. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, the Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more like an ordinary home for most people. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, homelike environments with people having a choice over who they live with. We have included in recommendations on quality assurance that Commissioners of services for people with a learning disability and behaviour that challenges should commission services to meet set service service-level and individual outcomes, and ensure that service providers to show evidence of achieving these outcomes. These outcomes should be used in measures of performance management.
East London NHS Foundation Trust	Short	26	29	1.9.2	Re "specialist in behaviour that challenges" there are no specifications regarding qualification level or experience for this term. If NICE cross referenced this with PBS Academy this would make this clearer to implement consistently and ensure the right level of expertise is involved. It would also be beneficial to further describe the scope of this access, i.e. many organisations now have a behavioural lead, however they are responsible for behavioural support across the organisation, so it is unlikely they will have direct support or knowledge of individual clients, or would consulting or commissioning for a "specialist in behaviour" to oversee an organisation fulfil this recommendation?	Thank you for your comment. We agree and we have revised this definition and removed the term when used as a profession title. We have kept the term behaviour support to be a generic term for behavioural interventions that are in line with the evidence based interventions recommended in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the Positive Behaviour Support framework is provided for people to find more detailed information.
East London NHS Foundation Trust	Short	28	7-10	1.9.5	The general principles of care section regarding support for staff reads that staff should be supported to "recognise and manage their own stress". We have concerns that this places too much responsibility on the staff and not enough on the system to support them. We know from Winterbourne View that abuse of people with a diagnosis of learning disability can be promoted in systems that do not adequately support their staff to process the emotional impact of their work. The responsibility on the system to support staff through reflective spaces etc should be much more explicitly made.	Thank you for your comment. The Guideline Committee agree that it is very important that staff feel they are supported in their work and wellbeing. The full recommendation referenced in this recommendation includes that Health and social care provider organisations should ensure that all staff get personal and emotional support. After careful consideration we think that this is adequately covered in the recommendations in this section and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to this relevant section in the clinical guideline has been included for people to find out more information.
East London NHS Foundation Trust	short	4	16-25	background	We think it is important to be clear about the historical cycle of institutionalisation and community care over the last 40 years for people with LD. Deinstitutionalisation in the 1980's, followed by the Mansell report in the 1990's and then the Francis Report/Winterbourne View in the 2000's indicate a cycle of promoting community care, but services being unable to provide this for people with more complex behaviour, leading to large proportions of these people returning to ATU's for long periods of time. We think this provides more justification of these guidelines.	Thank you for your comment. The background section of the guideline is limited to the more contemporary rather than historical policy and practice landscape and also points out that many of the targets of the Transforming Care Programme have not yet been met, which suggest the difficulties and complexities in designing a service model that works for people with learning disabilities and behaviour that challenges and their families.
East London NHS Foundation Trust	Short	6	5-9	How does it relate to legal duties and other guidance?	We note the absence of reference to the Human Rights Act. The management of people within ATU's and not under section places significant breeches to people right to liberty and right to family life. Although the guidelines do include direct reference to the MCA 2005 – we are curious as to the absence of the HRA.	Thank you for your comment. We have added reference to the Human Rights Act 1998 in the list of relevant legal duties and guidance.
East London NHS Foundation Trust	Short	8	3-9	1.1.1	We welcome the recommendation for a joint lead commissioner across health, social care and education. We also welcome that statement that the lead commissioner to have 'in-depth knowledge and experience of working with people with LD & behaviour that challenges'. We note there are no clear	Thank you for your comment. We hope that this recommendation will support the development of CPD requirements for commissioners in this field.

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					standards for this and wonder whether specific CPD requirements/suggestions for commissioners who are responsible for services for those at risk of developing or currently displaying behaviour that challenges. With the aim to enhance deeper understanding of current best practice inherent in this recommendation.	
East London NHS Foundation Trust	short	general		General	There is no specific mention of incident recording & reporting in this guideline. It is mentioned in the "Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges" May 2015 in relation to instances where restraint has been used. It may be helpful to include them again her as well as an emphasis on staff support and debrief procedures.	Thank you for your comment. After careful consideration, we think this is adequately referred to in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the clinical guideline is provided where appropriate for people to find more detailed information.
East London NHS Foundation Trust	Short	general	general	General	There is an emphasis on training and support for individual staff but a lack of emphasis on who should embed the PBS approach within services. There is not enough emphasis on the provider organisation's responsibility for developing the right environment and embedding of PBS.	Thank you for your comment. After careful consideration, we think that this is covered in the recommendation 1.9.5 that organisations should ensure that staff have supervision and support, in line with the recommendations on staff training, supervision and support in 'staff training, supervision and support' in the general principles of care section of the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the relevant section of the clinical guideline is provided for people to find more detailed information.
East London NHS Foundation Trust	short	general	general	General	There is a lot of focus on crisis. It would be good to see more focus on what services can do to, as much as possible, avoid people developing challenging behaviour in the first place (ie proactive interventions around training, support and service development.	Thank you for your comment. Several recommendations have been revised to place greater emphasis on supporting families, and on prevention and early intervention to prevent crisis. Specifically, the Aims and Principles of the guidelines, section 1.4 heading has been changed to emphasise that community services should be Services in the community – prevention, early intervention and response. Recommendation 1.4.11 has been revised to state that when reducing the level of support from more intensive services, lessons should be learned to inform future early intervention and prevention services and support crisis plans.
Enfield Integrated Learning Disabilities Service	Easy Read Slides			general	general	Thank you for your comment.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		general	It was mainly easy read and easy to understand but it was too long for most people to want to read, it could be simplified further. The artwork was good.	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		general	The easy read version should have page numbers on it; it is difficult to go back to things to refer to things without page numbers. Also difficult to discuss in a group without page numbers.	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		general	Asking what people think - people agreed with this and how it was written but said that it is no good unless the people making the decisions listen and take note of what is being said. People had examples of where they had said what they need and it had not been taken on board; they had not got what they wanted.	Thank you for your comment. The Guideline Committee gave careful consideration to the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.

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Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		general	Help them decide how to spend it- people felt that sounded as if they were being told how to spend their money. Maybe change to "Help them decide how they went to spend it." People generally felt the next few pages were good but it often didn't work in practice.	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		general	Specialist help for behaviour that challenges: last bullet point People felt that having to wait eighteen weeks was far too long.	Thank you for your comment. The 18 weeks was set as a limit and not as a standard, however this was not clear to many. We have revised recommendation 1.4.8 to make sure that a response is based on a person's individual assessment of need and risk, we have created a new recommendation from this (1.4.9) to say that lead commissioners should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support, and ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		Slide 10	Giving people control over how money for their care and support is spent. People felt that the second point "Tell them the different ways this money can be used" should also include "and listen to their suggestions"	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general		Slide 6	Providing the right support point 2 Make a plan for all the support people need now and in the future - people felt this should include reviewing it regularly in case needs have changed. I think this is mentioned later on.	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general	general	general	Help in a crisis -point 3 Give them a telephone number that they or their family can ring - people had had experience of being given a telephone number which no-one answered - to add working telephone number which will be answered regularly.	Thank you for your comment. The Guideline Committee also thought this was very important to people. We have said in the recommendation that the telephone line should be staffed by people with skills and knowledge about the needs of people with learning disabilities and behaviour that challenges, and specialist skills in mental health problems.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general	general	general	Staff Skills - people felt there were too many changes in their social workers and support workers which led to them feeling insecure or things going wrong because things were not communicated properly. One person said over 30 years they had had 31 workers. Something should be put in about people needing to not have too many changes and when there are staff changes, there are good handovers and information important to the person is properly recorded and passed on.	Thank you for your comment The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general	general	general	Staff training - people were not sure if finding new staff meant advertising for people who would work in a certain way with people, of a certain faith or culture.	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general	general	general	The suggestion was made to involve people with LD and autism in staff training.	Thank you for your comment. We have passed this suggestion to the NICE team that produced the Easyread version.
Enfield Integrated Learning	Easy Read Slides	general	general	general	Having a named worker is good. Could this be the same person as the care coordinator? Would that person still be the named contact even when things were settled and going well, or could they 'discharge'?	Thank you for your comment. The committee agree that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff.

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Disabilities Service						
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general	general	general	Respite is important, but it is not just 'building based'. Sometimes respite in the home is best, where the person's family can go away and the person has staff to support them in their familiar environment.	Thank you for your comment. We will revise all references to respite to be short breaks. In recommendation 1.7. 1 we say this could include support at home
Enfield Integrated Learning Disabilities Service	Easy Read Slides	general	general	general	There was no specific discussion about transition, and this is often when things can go wrong.	Thank you for your comment. The Guideline Committee also considered transitioning in recommendation 1.6.4 and revised this to say that services should support smooth transitions between services in line with organising effective care in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Hertfordshire County Council	Short	10	19	1.1.10	In Hertfordshire we find that Care and Treatment Reviews provide good quality monitoring information. The challenge is to sustain the ongoing monitoring and action plans arising from CTRs.	Thank you for your comment. The committee sought to emphasise the need for ongoing review and continuous improvement in recommendation 1.1.14.
Hertfordshire County Council	Short	10	2		In order to maintain a single experience across the age ranges, C&YP contract monitoring would need to be aligned with that in adult services. In Hertfordshire's Adult Services Integrated Health and Care Commissioners carry out joint visits with the social care contract monitoring team to achieve the best outcomes.	Thank you for your comment. The guideline recommends an integrated approach to commissioning, including an overall lead commissioner (recommendation 1.1.1).
Hertfordshire County Council	Short	11	1	1.2	Capacity and consent can get used as obstacles for good person centred working.	Thank you for your comment. The committee considered carefully the existing barriers to high quality care and support and developed recommendations they thought would help overcome them.
Hertfordshire County Council	Short	12	13	1.2.8	It would be desirable to build up choices for provision for independent advocacy and other routes for advocacy. There would be cost implications to provide this beyond statutory requirements.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of increasing access to advocacy. We have aimed to balance these considerations in the wording of the recommendations and consider the recommendations to be aspirational but achievable.
Hertfordshire County Council	Short	12	22	1.2.9	Named social worker: Where this has been trialled locally, this has enabled person centred approaches. Generally we feel operational staff and commissioners need to be trained in positive behaviour support and person centred active support across the age range to ensure a common approach.	Thank you for your comment and your support for the guideline. We agree with your comment related to staff competencies in positive behaviour support provided across the age range. However, we did not find the research evidence to be able to include active support as part of the recommendation. In recommendation 1.2.10 about 'named worker' this person might be the named social worker where this in in place.
Hertfordshire County Council	Short	13	18	1.2.13	A strategic approach to market management can stifle individualised choice / options. Framework contracts can help to manage markets and resources but can limit opportunity and stagnate providers. There still needs to be a focus on an individualised approach.	Thank you for your comment. The committee agree that flexibility and choice are important. See, for example, recommendation 1.1.5 about flexibility of funding.
Hertfordshire County Council	Short	13	29	1.2.15	Reviewing care and support: we agree with this but the capacity of operational teams to do this is may be an issue. More social workers may be required.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services.
Hertfordshire County Council	Short	14	10	1.2.16	Personal Health Budgets: The expansion of PHBs will be problematic pending the decommissioning of services to free up funding.	Thank you for your comment. We have revised recommendation 1.2.19 to read that local authorities and clinical commissioning groups need to 'ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences'. Think about using integrated personal commissioning where it is available to support this. The committee were also concerned about the financial context and budgetary constraints. They hope that the recommendations of this guideline will help advocate for the commissioning, or continued investment in, evidence-based services.

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Hertfordshire County Council	Short	15	28	1.3.4	NICE guidelines should be reviewed against person centred active support and positive behaviour support.	Thank you for your comment. The information provided in this welcome pack should relate to the recommendations in the clinical guideline in the section on the Support and interventions for family members or carers. We have provided a hyperlink to this section for people who wish to know more. NICE guidance focuses on 'what works' and evaluates the impact of guidance, standards and advice on the health and care system, and highlights how evidence-based recommendations are contributing to strategic change and quality improvement more information on NICE review of impact can be found here: NICE uptake and impact report March 2017
Hertfordshire County Council	Short	16	22	1.4.1	Often people are not known to Adult Disability Services until after they have come into contact with the CJS. Hertfordshire has commissioned the Offending Behaviour Intervention Service (OBIS) for adults who have had contact / are at risk of contact with the CJS.	Thank you for your response. We will pass this information to our resource endorsement team. More information on endorsement can be found here: (https://www.nice.org.uk/about/what-we-do/into-practice/endorsement)
Hertfordshire County Council	Short	17	18	1.4.3	Need to ensure that there is availability of people who could specialise. There needs to be a shared understanding of learning disabilities in C&YP Services and an associated change in language. The challenge is to replicate good practice for under 18s and for people with autism. Has this been signalled to Health Education England and universal services to ensure training and skills available? Good practice: Adults: Community Assessment & Treatment Service which includes Offending Behaviour Intervention Service, Positive Partnerships Team (working with individuals and their families / carers). Transforming Care Team Health pathway: community nurses / Intensive nursing. C&YP – Positive behaviour, Autism, Learning disability and Mental health Service (PALMS)	Thank you for your comment. In the recommendation we provide suggestions about how to ensure there is the availability of practitioners with the relevant skills including employing practitioners within the community learning disability team or by developing close links with practitioners in other relevant services. The Guideline Committee agree that the level of service and good practice needs to be replicated for children and young people and this is represented in children and young people services section (1.6) of the guideline.
Hertfordshire County Council	Short	17	5	1.4.2	Are there national specifications for specialist intervention and early intervention?	Thank you for your comment. We are not aware that there are any other overlapping guidelines for prevention and early interventions.
Hertfordshire County Council	Short	18	21	1.4.6	Sometimes the challenge is that people may be diverted from the criminal justice system when it would be more appropriate for them to be in the CJS.	Thank you for your comment. We have emphasised in the recommendation that community learning disability teams should maintain good communication links with the police and liaison and diversion teams. We hope that if communication is both ways that CLDTs could advise the CJS when they think it would be more appropriate for a person to be in the CJS.
Hertfordshire County Council	Short	18-20	18/620/18	Community services	Services set out in these paragraphs are provided for Adults in Hertfordshire.	Thank you for your comment. We are glad that these recommendations will support developments in this area and that areas are already implementing these recommendations of good practice.
Hertfordshire County Council	Short	20	19	1.5	Housing: In Hertfordshire one of the barriers is the cost of local housing and the availability of affordable properties.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Hertfordshire County Council	Short	21	1	1.5.3	People need to know their legal rights and local authorities need to challenge providers who want to revoke tenancies.	The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation. We have revised recommendation 1.5.3 to say Where possible ensure that, wherever people live, they have security of tenure in line with the Real Tenancy Test. We have included in the recommendation 1.1.10 about quality assurance of service that Commissioners of services for people with a learning disability and behaviour that challenges should commission services to meet set service service-level and individual outcomes, and ensure that service providers show evidence of achieving these outcomes, including stability of placements.

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Hertfordshire County Council	Short	21	3-11	1.5.4	Good practice: individualised services; CTRs / CETRs / local preventative model.	Thank you for your comment. The Guideline Committee agree that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
Hertfordshire County Council	Short	24	22	1.7	Respite Care: We have found providers are reluctant to develop crisis prevention services – bed based or non-bed based. Families of C&YP strongly value respite, both homecare and away from the home. Short term crisis intervention services commissioned from creative therapy practitioners.	Thank you for your comment. The Guideline Committee was in agreement regarding the importance of prevention and early intervention and short breaks and aimed to highlight this in this recommendation specifically and also in the guideline more generally.
Hertfordshire County Council	Short	25	13	1.8	Inpatient Services: CTR / CETR leads are in place. The commissioning role pays close attention on ensuring the appropriateness of admissions, supporting discharges once treatment has been completed, reducing re-admissions. This reduces the length of stay and improves assessment and treatment. Appropriate community support means that admissions are for Mental Health and not behavioural issues.	Thank you for your comment. This section relates to how to use inpatient admissions in an appropriate way, with an emphasis on people returning home as soon as possible.
Hertfordshire County Council	Short	8	15	1.1.3	Regional services In Hertfordshire pooled budgets have yet to be achieved for C&YP; this would need to be addressed before a wider strategic partnership could be formed. Regional services would impact on the health and social care infrastructure in the host authority area. E.g. □ local authority social care is responsible for safeguarding □ Specialist health provision would be the responsibility of local health provider / CCG. This increases the work of health and social care teams. Consideration would need to be given to how this additional work could be supported / compensated by other commissioning areas.	Thank you for your comment. The committee considered current practice and good practice in developing the recommendations. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.
Hertfordshire County Council	Short	8	2	1.1.1	In Hertfordshire the lead commissioning role across the areas listed would be the biggest impact on practice. The commissioning of adult commissioning functions listed is split across a number of different organisations and there are different arrangements across C&YP services. In Hertfordshire there are joint commissioning arrangements across health and social care for adults' services but not in C&YP services. Service reviews and staff change process could have cost implications.	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Hertfordshire County Council	Short	8	23	1.1.5	Identifying need: C&YP services don't collect data which specifically identifies numbers of children with a learning disability. The complete identification of cohort would require access to health databases as well as those managed by the Local Authority; there would be significant barriers to achieving this. There are also issues about the consent to share data. Further work is needed to identify where information is held and with whom it sits. In Hertfordshire we have found that there is very poor information on the numbers of people with learning disabilities / autism in the criminal justice system.	Thank you for your comment. The Guideline committee agreed that there was variation in practice in collecting data on children and young people, and also adults when planning for services. We have listed examples of information sources that can be access by Local Authorities to plan services based on local level data currently used. National population and prevalence data can be used to estimate local population level needs. We are therefore not recommending a new data management systems, rather than better use of existing available, information sources.

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					Any new information / data management system would have significant cost implications. Improving data collection by other organisations. Review information governance legislation / guidance.	
Hertfordshire County Council	Short	9	17	1.1.6	Herts TCP have had the aspiration to develop a single care pathway. This has not yet been achieved as whilst we have jointly commissioned adult LD services, this is not yet in place for C&YP Services. We feel this pathway would need to be around neuro-developmental conditions as there is no learning disability diagnosis in childhood. Regional contracting would require a lead commissioning role. Operational level sign up would also be required. The paper identifies people with learning disabilities and behaviour that challenges. What about people without challenging behaviour? Who would host the lead commissioning role? Could the lead commissioner be the chair of the TCP Board?	Thank you for your comment. We agree that there should be a care pathway that is person-centred, this is reflected in the Aims and Principles and recommendation 1.1.2. These say there should be a whole-life approach to planning for services. The population of focus for this guideline is people with a learning disability and who display behaviour that challenges, as they had been identified as a population at greater risk of poor outcomes and barriers to accessing good quality care. People with learning disabilities who do not display behaviour that challenges are the focus of different NICE guidelines. NICE produces interactive flow charts to help people navigate between different guidelines that are relevant to a population or condition. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Hertfordshire County Council	Short	9	27	1.1.7	The responsible psychiatrist may take over the responsibility for the risk. This means there is no sharing of risk. In Hertfordshire we already share responsibility with providers. All good commissioners should have an effective provider / commissioner relationship which is conversational, dynamic and ongoing.	Thank you for your comment and the example of how this is working in practice. This has been edited to include reference to working with other organisations, to reflect that the people involved will vary depending upon the specific situation and context.
Hertfordshire County Council	Short	General		general	The recommendations only refer to learning disabilities. Equal consideration also needs to be given to people with autism who often fall between services.	Thank you for your comment. The population of this guideline includes people with autism who also have a learning disability and we have revised the background section to make this clearer. NICE have produced a guideline for people with autism who do not also have a learning disability: Autism spectrum disorder in adults: diagnosis and management Clinical guideline [CG142]
Hertfordshire Partnership University NHS Foundation Trust	Short	10	19	1.1.10	There is a shortage of experts by experience in post to participate in this type of work. Having a national push to increase these posts and provide some training for post holders would be very valuable in making sure experts by experience can be more involved in quality assurance tasks.	Thank you for your comment. The committee – which also included experts by experience - agreed strongly about the importance of their inclusion in this work and the need for appropriate support to enable this. Stakeholder comments are reviewed by NICE to inform their work to plan support activity to accompany the guideline.
Hertfordshire Partnership University NHS Foundation Trust	Short	10	5	1.1.8	We feel this recommendation could contain more specific information about other possible outcome measures to use. For example, explicitly linking with the STOMP (Stopping over-medication of people with a learning disability, autism or both) strategy outcomes for reduction of anti-psychotic medications. Some specific PBS (Positive Behavioural Support) outcome measures could also be included here, such as, the Behaviour Problem Index-Short Form (BPI-S) to measure change in the intensity and frequency of behaviours that challenge; the Guernsey Community Participation & Leisure Assessment - Revised (committeePLA-R) to look at changes in quality of life. Rates of admission to hospital could also be included here as an outcome measure.	Thank you for your comment. We agree it is helpful to highlight the importance of regularly reviewing medication. This is covered in recommendation 1.2.22. We reference the recommendations set out in the NICE guidelines - (Managing medicines for adults receiving social care in the community. NICE guideline NG67) for adults receiving social care in the community and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for people with a learning disability and behaviour that challenges using inpatient services.
Hertfordshire Partnership University NHS	Short	12	5	1.2.5	This same point should be made about adults (not just children) with a learning disability, in terms of including them in decisions. Even someone assessed not to have capacity to make decisions should still have information shared with them in a way that is consistent with their communication needs and level of understanding. For some this may mean sharing very basic information and /	Thank you for your comment. We note that this is in line with the Mental Health Act We agree it is useful to highlight how the guideline relates to other guidance and legislation. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation. To address providing information compatible with people's communication needs

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Foundation Trust					or including them in parts of decisions where they are not able to contribute to the whole decision.	We have revised recommendation 1.2.6 to state that staff working with children, young people and adults with a learning disability and their families should find out their information and communication needs, record them and share this information with everyone working with them in line with the Accessible Information Standard.
Hertfordshire Partnership University NHS Foundation Trust	Short	13	19	1.2.13	It is an important aim to match staff skills to the person's needs but the reality of the care sector is that it can be difficult to get a permanent staff team rather than constantly changing agency workers, let alone get a team with specific skills to match the person's needs. There should be some attempt to acknowledge the crisis in the care sector and a consideration of whether some of these barriers can be overcome and how.	Thank you for your comment. This recommendation is directed at service providers and agencies that commission services and states that all staff who work with people with a learning disability and behaviour that challenges should have the skills necessary to work with that particular person, and that service providers and commissioners need to give consideration to the specific needs and preferences of that person. More information on the skills and values of staff are in section 1.9. The Committee are aware that this may not be possible in all instances but thought it important to recommend and highlight best practice, based on the research evidence. They consider the recommendation to be aspirational but achievable. Further discussion on how research evidence and evidence from expert testimony was interpreted to form the recommendations is discussed in more detail in the 'Evidence to recommendations' section in the full guideline. The recommendation was based on evidence statement SM24 which talked about the personal qualities of staff in services that worked well. It also found staff characteristics and behaviour that people did not like, such as over-involvement in staff in their lives that did not match to their needs. This was also supported by the expert witness testimony from the Devon case study who also suggested that matching the person and their key support workers with similar interests was one of the key things for services and commissioner to get right.
Hertfordshire Partnership University NHS Foundation Trust	Short	15	8	1.3.1	The barriers to providing family carers with training in how to respond safely to behaviours that challenge being presented that it has not been possible to prevent, should be acknowledged here. While paid carers have a legal right to such training, family members continue to find it extremely difficult to access support that may help, alongside essential proactive approaches, to maintain placements at home (e.g. simple self-protective / breakaway techniques). Changes are required in how Services approach this issue to ensure needs are met adequately.	Thank you for your comment. In the 'putting this guideline into practice' section we emphasise the need for local authorities and health services to provide comprehensive support for families including the need for 'ongoing training and support for their caring role from specialist services, including positive behaviour support services'. We say in recommendation 1.3.2 that training for families and carers needs to be in line with recommendations 1.7.1 and 1.7.2 in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11)
Hertfordshire Partnership University NHS Foundation Trust	Short	17	21	1.4.3	This list should include individual therapies (e.g. access to talking therapies, art therapies, music therapy).	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically.
Hertfordshire Partnership University NHS Foundation Trust	Short	17	6	1.4.2	The guideline could be clearer about what is meant by 'specialist prevention and early intervention'. Does this mean getting involved early once difficulties have been identified or does it refer to working with families at risk, to reduce the risk of behaviours that challenge developing in the first instance?	Thank you for your comment. Specialist prevention and early intervention has the same meaning in this guideline as to how it is defined in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). It covers specialist assessment, support and intervention services.

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Hertfordshire Partnership University NHS Foundation Trust	Short	19	13	1.4.9	The ability to offer an out-of-hours helpline is very dependent upon local resources, so this recommendation may need to be less specific or more resources are likely to be needed in community teams to be able to provide such a service.	We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialists skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or inpatient admission due to the lack of available specialist support in the community. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Hertfordshire Partnership University NHS Foundation Trust	Short	19	17	1.4.9	The suggestion that teams need sufficient capacity to provide a response within one hour does not feel realistic in practice. Even if a duty system is in operation, workers may already be out and crises can take longer than one hour to reach a point where duty workers are no longer needed. It may be that increased staffing levels would be required to meet this recommendation even in services where crisis responses are currently offered. In addition, we felt that the guideline is not clear about the type of response being recommended (e.g. a phone response within a set time-frame would be easier than a face-to-face contact).	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Hertfordshire Partnership University NHS Foundation Trust	Short	20	18	1.4.15	This statement after could include 'and effectively manage risk' after 'get the right support'.	Thank you for your comment. We have revised the wording of the recommendation as you have suggested.
Hertfordshire Partnership University NHS Foundation Trust	Short	21	11	1.5.5-	Despite ideal housing model recommendations, many of the services we support continue to place more than four service users together in one setting. This would be a very difficult recommendation for local services to implement without commissioning changes and a drastic increase in finances to support the purchase of additional properties.	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life, and felt that it was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. For this reason the reference to a specific number has been deleted. The Guideline Committee interpreted the available evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home like is more like an ordinary home for most people.
Hertfordshire Partnership University NHS Foundation Trust	Short	24	7	1.6.9	This section would seem relevant to adults as well as children (e.g. ensuring a person is in the least restrictive environment and making sure placements are properly reviewed).	Thank you for your comment. Reviewing care of adults is covered in section 1.8.
Hertfordshire Partnership University NHS Foundation Trust	Short	28	6	1.9.4	This could also include the recommendation that staff are provided with training in using positive behaviour support approaches for people with learning disabilities and behaviour that challenges.	Thank you for your comment. After careful consideration, we think that this is adequately covered in the reference to recommendations in 'staff training, supervision and support' in the general principles of care section of the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), particularly the recommendation that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of behaviour that challenges. NICE guidelines aim not to duplicate guidance which is provided elsewhere. A hyperlink to the relevant section in the clinical guideline has been included for people to find out more information.

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Hertfordshire Partnership University NHS Foundation Trust	Short	8	21	1.1.4	We support the idea of a contingency fund for providers and have experience of this type of arrangement working well for service users we support. This has helped to avoid inpatient admissions when used well.	Thank you for your comment and support for this recommendation.
Hertfordshire Partnership University NHS Foundation Trust	Short	9	30	1.1.7	We feel that this recommendation could be made more specific by clearly outlining examples or options for alternative ways of managing risk (e.g. through the implementation of positive behavioural support plans; through careful resource planning to ensure adequate staffing levels are in place etc).	Thank you for your comment. The committee agreed this wording as this recommendation seeks to emphasise the joint responsibility for preventing placement breakdown. More detailed recommendations on prevention, early intervention and response can be found in section 1.4 which has been re-titled to make this clearer.
Home from Home Care	Short	10	19	1.1.10	If we accept that valuing people is the policy driver then every locality should have a learning disability partnership board preferably jointly chaired with someone with a LD/autism and a membership that includes all stakeholders. Please reference these boards and don't reinvent the wheel.	Thank you for your comment. The committee discussed the considerable variation in practice and also had concerns there are not always effective, functioning boards in place. This recommendation seeks to allow for local models to continue where they are effective, while also ensuring consistency more widely.
Home from Home Care	Full	105		General	This section and references to clustered versus clustered accommodation is a key finding. "The limitations of the findings are that most studies are cross - sectional so it is unclear whether outcomes or costs change over time between settings. Another limitation is whether differences in outcomes are inherently due to setting design or whether it is due to poor management and organisation". You then go onto reference international studies to challenge that but then finally conclude "The review is limited by the use of narrative synthesis, not reporting the quality of included studies, making it difficult to assess the reliability of the findings, and not providing detailed information about sample characteristics, making it difficult to generalise findings. Furthermore, the review includes all adults with intellectual disabilities and was not specifically focused on individuals with challenging behaviour, although they may have been included". We need NICE to come off the fence on this issue and make clear that there is no compelling evidence for the dispersed versus clustered model.	The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, the Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home like and more like an ordinary home for most people. The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation.
Home from Home Care	Short	14	9	1.2.16	There is not a single reference to personal health budgets. NHSE has set targets for those with LD/autism to be recipients of a personal health budget. Please refer to them and amend the guideline accordingly. Home from Home Care	Thank you for your comment. We have revised recommendation 1.2.19 to read that local authorities and clinical commissioning groups need to 'ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences'. Think about using integrated personal commissioning where it is available to support this.
Home from Home Care	Short	16	21	1.4.1	Services in the community must include references to care homes as a specific entity as part of community capacity. References should also be made to the positive outcomes that individuals have from such personalised living arrangements. There are a plethora of peer reviewed research publications to support this inclusion. There is also the Care Quality Commissions own inspection data that shows that care homes with up to 10 beds are more likely to be rated outstanding than care homes with 4 beds. We cannot attach that analysis into this submission as it breaches your requirements but we will send that analysis under separate cover. We fully expect to see the CQC inspection data referenced in the final guideline as you and they put a good deal of store in each of your products.	Thank you for your comment. The Guideline Committee agree that personalised living arrangements were important to people. The Guideline Committee felt that it was more important that people had a choice over where they lived, that the type of accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, the Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home like and is more like an ordinary home for most people. The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation.

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Home from Home Care	Short	2	General		Your guidance should be unambiguously clear that it applies to NHSE, CCGs' councils and to all regulatory bodies like CQC(organisational regulator) and professional regulatory bodies like HCPC, RCGP etc	Thank you for your comment. The audience for the guideline is: • Commissioners of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges • Providers of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges • Health and social care practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers. NICE do not typically make recommendations aimed at national bodies such as national commissioners, regulators and professional bodies but does work in partnership with these bodies to ensure the guidelines are implemented. NICE and CQC have an agreement around how NICE guidance is used in inspections.
Home from Home Care	Short	20	20	1.5.1	There is a housing crises in the UK. You cannot include this section without a reference to housing policy and where needs for those with LD and autism fits into that. If you fail to include that policy reference you will further degrade the relevance of the guideline.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Home from Home Care	Short	22	4	1.5.8	There is no policy references to the NHSE guidance for GP's on meeting the health care needs of those with LD and autism. There are also guidelines through VODG and NHSE on prescribing and managing dementia with those with LD. Please include these references into the final guideline.	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation.
Home from Home Care	Short	27	14	1.9	There is a staff shortage in the NHS and social care. This guidance without references to the policy and guidance about recruitment, retention and context in which this has to happen will further degrade the guideline. There is no reference to the skills for care values base recruitment or the HEE guidance for recruiting doctors and nurses.14	Thank you for your comment. We have referenced the skills needed in staff training supervision and support in the clinical guidelines. Methods of recruitment of staff for health and social care is out of scope for this guideline.
Home from Home Care	Full	33		General	We quote "However, there is limited evidence about the acceptability, feasibility, effectiveness and cost effectiveness of different house size/ residency for people with different support needs. It is important that commissioners and service providers have high quality evidence to base housing investment decisions on and to ensure good outcomes for people living in different types of housing with different support needs." This needs to feature more prominently in the guideline to make sure that collectively evidence is provided on what works (see reference to CQC inspections data) and that we are thin on the ground with evidence in this sector.	Thank you for your comment. The Committee agreed on the importance of accommodation as a determinant of health and wellbeing. The need for cost effectiveness evidence is a view shared by the committee which led to them making a research recommendation which they hope will ensure the gap in evidence is addressed in the future. While there was not strong evidence to support recommendation of one type of housing over another, or the maximum number of residents to maximise choice, control and wellbeing, the Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be in small, homelike environments with people having a choice over who they live with. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another. The Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home like and more like an ordinary home for most people. The Guideline Committee favoured accommodation which offered security of tenure and a split between supported service provision and accommodation.
Home from Home Care	Short	4	16/17	Background	Policy has not changed and valuing people is still the only government policy on the table. The reference to Mansell 2 and its status is clear "This report is issued as best practice guidance to councils with social services responsibilities	Thank you for your comment. We agree and have revised the text to reflect this. It now reads: "This guideline was developed in a context of developing policy and practice"

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					and health bodies. It is not mandatory and no extra resources will be provided for its implementation. Councils and health bodies should take it into account in setting their own priorities and policies. It will also be useful to people using services, their families and representatives, staff and service-providing organisations as a statement of best practice".	
Home from Home Care	Full	46		General	There was little high quality evidence that could tell us which types of services are effective and cost - effective and there were gaps in some areas. It makes devising a guideline with any real meaning rather difficult to design let alone implement. Please reflect this in your final guideline.	Thank you for your comment. We agree that there was a lack of direct, robust research evidence on the effectiveness and cost effectiveness of different kinds of models of service delivery for people with learning disabilities and behaviour that challenges. Research into social care provision and models of health and social care service provision is in in its infancy. In addition to the research evidence of effectiveness and cost effectiveness, Guideline Committees bring different kinds of knowledge from their professional experiences and the knowledge of people with lived experience of services. We have included the deliberations about the available research literature and the Guideline committee's interpretation into recommendations in the 'Evidence to recommendations' section of the full guideline. Where research evidence is lacking, the Committee can request evidence from expert witnesses and make research recommendations. The need for cost effectiveness evidence is a view shared by the committee which led to them making a research recommendation. Research recommendations developed by guideline committees are reviewed by the National Institute of Health Research (NIHR) and inform research priorities for NICE and other commissioners and funders of health and social care research. The guideline is based on the best available evidence at this time.
Home from Home Care	Short	5	14	Backgrou nd	Please can you be clear what the status is of the national service model for commissioners? Can you please be clear and unambiguous that this model does not specify that SIX BEDS is the optimum number for residential servces	Thank you for your comment. This guideline continues the direction of travel of the interim service guidance (ADASS, LGA and NHS England (2015) Supporting people with a learning disability and/or autism who display behaviour that challenges including those with a mental health conditions: Service model for commissioners of health and social care services). In the guideline, we do not recommend an optimum number of residents for any setting. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life, it was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, the Guideline Committee interpreted this evidence and evidence from expert witness together with their practice and experiential knowledge to understand this to mean that small numbers were more naturally home like is more like an ordinary home for most people. The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation
Home from Home Care	Short	5	22,23,24	Backgrou nd	There is no explicit academic references to the claims made here and this is picked up later on in our response to the claims made and lack of underpinning evidence base	Thank you for your comment. Full references to the research evidence underpinning the recommendations are to be found in the full version of the guideline. The research evidence is also informed by the views of people who use services and their families on what is important to them in their care and support and further details of the guidelines considerations of the evidence and cost implications are found in the linking evidence to recommendations section of the full version of the guidelines.
Home from Home Care	Short	7	18,19,20	Aims and principles	These are ambitious claims that a NICE guideline will deliver social engineering. Can you identify evidence sources that NICE guidance has done this in other policy spaces please. If not withdraw the ambition.	Thank you for your comment. Social engineering is not in NICE remit. While not mandatory, we hope that these recommendations of good practice, based on research evidence, and interpretation of the evidence by professionals, academics and experts by experience, supports the commissioning and development of services that place greater emphasis on supporting families, and prevention and early intervention, which is in line with the current policy context of Transforming Care and supported by evidence based intervention in the clinical guideline.

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Home from Home Care	Short	8	General	1.1.5	There is no reference to Joint Strategic Needs Assessments (JSNA) or to the Market Position Statements of the councils. Every CCG/Council should have a JSNA and every council a MPS that signals to providers their intentions. Please reference these documents which have as much status as all the other guidance documents referenced in the guideline.	Thank you for your comment. We have referenced the Market position statement in recommendation 1.1.9. We have not referenced the JSNA as an objectively collected source of information but that the other sources of information we list can inform completing the JSNA for local area planning.
Home from Home Care	Short	8	General	Achieving change	There is no reference to the role and function of NHS England (NHSE) in terns of commissioning functions. NHSE commissions all children and young people Tier 4 services and all adult mental health services including those for in patients with LD/Autism and mental health services and forensic services. They must be included in the strategic planning context and their role referenced in relation their responsibilities and how they work with CCGs and Councils.	Thank you for your comment. We have referred to NHS England in reference to the of the policy context in response to the report Transforming Care. a national response to Winterbourne View Hospital (Department of Health 2012). The report calls on local authority and NHS commissioners to use integrated commissioning arrangements to transform care for vulnerable adults with learning disabilities and autism, and mental health conditions or behaviours described as challenging. This guideline takes into account the direction of travel in Transforming Care. It aims to complement this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges.
Individual - Biza Stenfert Kroese	full	general		general	Please correct Kroese, B reference to Stenfert Kroese, B. & Rose,J. and refer to the published papers: Stenfert Kroese, B., Rose, J., Heer, K. & O'Brien, A. (2013) Mental health services for adults with intellectual disabilities - what do service users and staff think of them? Journal of Applied Research in Intellectual Disabilities, 26(1), 3-13. Stenfert Kroese, B, Rose, J., Heer, K, & O'Brien, A. (2013) Gender issues for people with intellectual disabilities and mental health problems – asking what service users and staff think. Advances in Mental Health and Intellectual Disabilities, 7(4), 181-190.	Thank you for your comment. We have corrected the way that we have cited your study in the guideline. The paper we reviewed was Stenfert, Kroese and Rose (2011). The other references were not identified from the title and abstract as containing the keywords to the search strategy for this population, (learning disability AND behaviour that challenges) from the search, but are indexed in some of the databases that were searched.
Individual - Biza Stenfert Kroese	full	general		general	Although there is mention of consideration for cultural and sexual identity difference, it fails to address gender differences and appropriate service responses to male and female service users. The paper referenced above was designed to address this issue and explores the views and experiences of staff and serive users. Although this research concerns people with mental health problems, some preliminary suggestions for further investigation may be considered in this document: 1/ collect further evidence for the adult population with intellectual disabilities on the prevalence and causes of mental health problems as well as on mediating and protective factors specific to gender so that interventions can be designed to meet the needs of both men and women most effectively 2/ research the manner in which men and women with intellectual disabilities express their emotions and seek help for emotional problems in order to identify possible sex differences which lead men with intellectual disabilities to be less likely in receipt of timely support for mental health problems 3/ evaluate the benefits of same sex support groups for men and women with intellectual disabilities and mental health problems, particularly groups which adopt a community psychology approach (Smail, 2005), i.e. the use of psychological methods to enrich the lives of the powerless, with a focus on change and action to improve well being and tackle the causes of health inequalities 4/ educate support staff in the socio-economic causes of mental illness and improve their competence to recognise and treat mental health consequences of domestic violence, sexual abuse and acute and chronic stress 5/ investigate the effectiveness of group and/or mentoring interventions for adults with intellectual disabilities and mental health problems to encourage respectful relationships between the sexes by exploring differences and similarities between men and women	Thank you for your comment. We found few studies of robust design that looked at gender differences in service needs. We were also clear that we did not conflate behaviour that challenges with mental health problems, and people with learning disabilities with mental health problems were the topic of another guideline and so out of scope for this guideline. However, we consider differences in service provision and access for each recommendation for people with protected characteristics, including sex and gender in the Equality Impact statement. 1. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) included a review of gender as a risk factor for people with a learning disability developing behaviour that challenges, and we refer and hyperlink to this section of the clinical guideline where appropriate for people who wish to know more. 2. The clinical guideline also considers sub-group analysis by gender for evaluations of interventions where this data is available. While primary research is not in the remit of NICE guidelines, the Guideline Committee can make research recommendations where evidence is lacking. 3. Mental health of people with learning disabilities (but not behaviour that challenges was the topic of another NICE guideline (Mental health problems in people with learning disabilities: prevention, assessment and management. NICE guideline NG54) and out of scope for this guideline. You may be interested in other guidelines that NICE have produced on the topics of child abuse and neglect (Child abuse and neglect. NICE guideline (NG76), domestic violence and abuse (Domestic violence and abuse. Quality standard (QS116), anxiety disorders (Anxiety disorders. Quality standard QS53). The NICE website provides an interactive flow chart of overarching themes that brings together overlapping guidance and quality standards to help people navigate between relevant guidelines. The socio economic interaction and sex and gender differences in outcomes will have been considered for all NICE guidelines as part of the equality impact assessment for people with protected characteristics and sub-group analysis for outcomes where data allows.

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					6/ investigate the effectiveness of training and supervision aimed at supporting both male and female staff working with adults with intellectual disabilities and mental health problems in developing the interpersonal qualities (traditionally considered female), relevant to listening skills and expressing empathy.	
Individual – Claire de Than	Short			1.9.1	1.9.1 Last bulletpoint should end 'and human rights'	Thank you for your comment. We have revised this recommendation based on your suggestion
Individual – Claire de Than	short	11		1.2.4	1.2.4 'Staff working with people with a learning disability should actively involve…' I do not consider that this statement goes far enough to comply with the requirements of human rights law, the UN Convention on the Rights of Persons with Disabilities or even the Mental Capacity Act. The presumption of capacity and the right to make as many decisions as possible should be explained and be central to the guideline. Further, the statement that '…staff must follow the Mental Capacity Act' in the same paragraph requires elaboration, since the MCA does not apply to all decisions, and so its exceptions and subsequent developments in case law should also be followed by staff. Staff should avoid substitute decision-making whenever possible.	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation. We have added the Human Rights act to the list of relevant legal duties and guidance. We have also revised this recommendation 1.2.2 to say that services should actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005. Recommendation 1.2.4 says to '1.2.4 Involve children, young people and adults' families, friends, carers or advocate if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental Capacity Act 2005. This should be done unless there is a compelling reason not to (for example if there are safeguarding concerns).' Please note that there is a forthcoming NICE guideline on decision making and mental capacity.
Individual – Claire de Than	short	13		1.2.11	1.2.11 Second bulletpoint should continue '… and works to support and maximise capacity'. Simple measures such as adjusting surroundings and avoiding triggers can make a huge difference in capacity assessments and appearance of capacity.	Thank you for your comment. We have revised this section accordingly.
Individual – Claire de Than	Short	14		1.2.17	1.2.17 Needs an additional bulletpoint, 'ensuring that the full range of support needs is met, including social needs	Thank you for your comment. The offer of direct payments and individual service funds is based on assessment of needs. In the section on Care and Support planning (1.2.14) we have said that care and support plans should meet the person's needs and preferences.
Individual – Claire de Than	short	22		1.6.3	1.6.3 'meaningful education' should explicitly include sex and relationships education, since vulnerable persons with disabilities often miss such education.	Thank you for your comment. The committee agree that it is important that children and young people with a learning disability have access to this type of education, however we think that the phrase 'meaningful education' will prompt people using the guideline to think about education in the broadest sense.
Individual – Claire de Than	short	24		1.6.8	1.6.8 Reference to Skype is both a brand name and a little retro! More modern technology exists and can be particularly effective, so some research here would be profitable.	Thank you for your comment. The committee made their recommendations on the basis of the research evidence and this often reported that Skype was used; however this recommendation is provided as an illustrative example, rather than a recommended method of communication.
Individual – Claire de Than	Short	25		1.7.2	1.7.2 Last bulletpoint should continue '…and choices about personal care, private life and lifestyle.'	Thank you for your comment. This recommendation has been edited accordingly.
Individual – Claire de Than	short	general		general	Human rights do not even receive a mention in the short version of the guideline, and hardly feature in the full version. They deserve elaboration in explicit terms whenever relevant, which is in fact throughout the document.	Thank you for your comment. We have added a reference and hyperlink to Human Rights Act referred to in the legal duties and other guidance section on page 6 of the short guideline.
Individual – Dr Tom Crossland	Full	20	20	1.4.9	I am concerned that this will maintain the crisis response model of care rather than focusing on crisis prevention using intensive input. It also seems unrealistic and inefficient to expect the resources to be available to guarantee a 1 hour response time.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.

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Individual – Ian Penfold	Short	26	23	1.8.9	Planning and review to support discharge Page 26 – The responsibility of the Local Authority should be mentioned here as delayed discharges are often caused by a lack of suitable local housing and support services. This should also specify the timely provision of aids and adaptions. Individual – Ian Penfold	Thank you for your comment. The wording of the recommendations follow on from other recommendations on building capacity in the community, which if implemented, would mean that delays to discharge due to lack of available services and supports, including housing (in recommendations within section 1.5.) in the person's home and ? community would minimised.
Individual – Ian Penfold	Short	General		General	Autism - These guidelines aim to reduce inpatient admissions in line with the Transforming Care Programme (TCP), however there is no mention of autism. Given that autism is a social communication impairment that affects (to a great or lesser extent but in ALL cases) understanding and using language, flexibility in thinking, social interaction and sensory processing which can mean a person with autism may display behaviour that challenges as a result of their neurodisability, irrespective of their IQ. For people with autism who display behaviour that challenges, there is therefore an equal need for functional behaviour analysis and positive behaviour support. Suggest that this guidance should refer to people who learning difficulties, autism or both – as recognised by, and in line with, the TCP. Including autism in this document would mean that people with autism who display behaviour that challenges are 'not left out in the cold'	Thank you for your comment. The scope of the guidelines includes people with autism and who also have a learning disability. After further consideration. The Guideline Committee agreed that this needed greater clarification and have revised the background section to make this clearer. However, the population is in line with the clinical guideline, NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), that accompanies this service guideline, who are as follows: • lower intellectual ability (usually an IQ of less than 70) • significant impairment of social or adaptive functioning • onset in childhood. NICE has also produced a guideline specifically for adults with autism spectrum disorders, (NICE (2012) Autism spectrum disorder in adults: diagnosis and management NICE guideline CG142).
Individual – Ian Penfold	Short	General	General		Personal Budgets – Currently there is not enough choice for those who would like to benefit from these but do not have the means to manage the budget themselves. A greater emphasis on the need for those responsible to provide the option of an Individual Service Fund for example would go some way towards addressing this shortfall. Further thought is needed to make the management and use of personal budgets more accessible for all.	Thank you for your comment. Recommendations 1.2.19 and 1.2.20 make reference to personal budgets and Individual Service Funds.
Individual – Ian Penfold	Short	General	General		Affordability - This draft is very comprehensive and for me includes the vast majority of things that are needed to address current failings. However the cost of complying with it will be a major barrier in the current climate. Commissioners are likely to declare much of the guidance as unaffordable and will use the defence, I have seen this before, that as it is only guidance they do not have to follow it. I fear that we may have to present this as 'must do's' rather than 'may do's' to have any impact.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Individual – Ian Penfold	Short	General	General		Medication - The inappropriate use of psychotropic medication has not been mentioned or referenced. This is vital part of ensuring that care is safe and appropriate.	Thank you for your comment. We agree it is helpful to highlight the importance of regularly reviewing medication. This is covered in recommendation 1.2.22. We reference the recommendations set out in the NICE guidelines: (Managing medicines for adults receiving social care in the community. NICE guideline NG67) for adults receiving social care in the community and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for people with a learning disability and behaviour that challenges using inpatient services.
Individual – Ian Penfold	Short	General	General		Staffing – I would welcome guidance about appropriate staffing levels to meet the need. Currently budget holders are paring costs down to a minimum and in some cases putting staff and patients at risk. We expect the Care assessment process and the Care plan to identify how safe, person centred and effective care is to be implemented and commissioners must implement this without compromise.	Thank you for your comment. We did not find any research evidence on staffing levels, so were not able to make any recommendations about what is appropriate. We did find research evidence about appropriate staff skills and values which is reflected in section 1.9 of the recommendations.
Individual – John McCulloch	Full	16	6	1.3.1	It may be helpful to have the list of specialist services expanded to include for example Arts Therapists	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet

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						those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Individual – John McCulloch	Full	18	19	1.4.3	Once again the list of professions within CLDT's needs to include Arts Therapies	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Individual – John McCulloch	Full	465	10	1.3.1	Arts Therapies needs to be included in recommendation 1.3.1	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically.
Individual – John McCulloch	Full	467	20	1.4.3	Arts Therapies needs to be included in recommendation 1.4.3	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges NICE guideline NG11) considered interventions. The clinical guideline did not find research evidence on music, dance and drama therapies and the Guideline Committee had not had experience of non-pharmacological therapies including music, dance and drama therapies to recommend them specifically.
Individual – Mary Busk	All	general		general	Lots of the right words but need people to be more aspirational for these CYP and we need more about how the words can be practically translated into meaningful life outcomes esp those in CFA 2014 - good health, community and friends, employment, supported/independent living. So can we please have an aspirations and outcomes section please? The Children and Families Act came about because there are very low aspirations for CYP with SEND and very poor outcomes especially for this group. You reference data but there is none: http://www.bacdis.org.uk/policy/dataset.htm	Thank you for your comment. We agree that outcome measures should be person-centred and have revised recommendation 1.1.10 to include measures that includes evidence from quality reviews and spot checking involving experts by experience and quality checks by user-led organisations. This is to ensure that the outcomes measured are those that are important to people and that these measures (in recommendation 1.1.13) should use these in their performance management of services. Our definition of learning disability (as opposed to learning difficulties) is in line with the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) that accompanies this services guideline and includes: • lower intellectual ability (usually an IQ of less than 70) • significant impairment of social or adaptive functioning • onset in childhood.

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					There are also languge issues between educarion and health and care – education refer to learning difficulty and not to learning disability. These also need to be reconciled. For example see the Residential Schools Report Footnote 8 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/657418/Good_intentions_good_enough_-_a_review_of_residential_special_schools_and_colleges.pdf	
Individual – Russell Woolgar	Full	9		1.2.9	This recommendation may be more problematic where individuals are 100% health funded and so do not have a social worker to act as a coordinator, this would be a CCG commissioner, less likely to act as a coordinator?	Thank you for your comment. We have revised recommendation 1.2.10 to include working in partnership with health and we have provided another example of who the assigned single practitioner could be, i.e. community psychiatric nurse.
Individual – Virginia Griffiths	Full		23	1.6.1	Any specialist CAMHS provision should also be included, for example locally I have an team within CAMHS for Looked after and adopted children (LAAC) who provide support based on needs related to developmental trauma and the behaviour challenges that arise from this.	Thank you for your comment. Children with behaviour that challenges who do not have a learning disability are not within the scope of the guideline.
Individual – Virginia Griffiths	Full		23	1.6.3	This section is really important in order to develop training for parents and carers on behaviour that challenges. Services are very limited and not available to all due to funding/tight gatekeeping of who can access the services/limited or no local provision.	Thank you for your comment and support for this recommendation. The Guideline Committee was also concerned about the financial context and funding issues. The committee hope that the recommendations of this guideline will help advocate for the commissioning, or continued investment in, evidence-based services.
Individual – Virginia Griffiths	Full	0	9	1.1.2	Parent carer groups should be included in the commissioning discussions so that local provision is tailored to the neds of children.	Thank you for your comment. This recommendation relates to joint commissioning across areas. The Guideline Committee agreed strongly that people and their families should be at the centre of commissioning their support package and this is addressed in detail in section 1.2.
London Borough of Sutton Council	Short	17	30	1.4.3	Is there a professional title which relates to behavioural therapists – I am conscious that Board Certified Behaviour Analysts might work with this clients group and there are a number of professionals through experience who would work with this group who have no professional qualification. I would suggest for clarity that 2 separate categories are created; □ Board Certified Behaviour Analysts Behaviour Specialists by experience	Thank you for your comment. We have removed the term from recommendations when used as a profession title. We have kept the term "behaviour support" to be a generic term for behavioural interventions that are in line with the evidence-based interventions in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). .
London Borough of Sutton Council	Short	19	26-30	1.4.10	An over emphasis on crisis response is problematic as an approach and creates a dependency culture around the support of clients. Reactive interventions by definition are more likely to unsustainable, lead to collateral risks and focus on containment rather than, working to facilitate behaviour change. It would be better to place more emphasis on providers and commissioners taking ownership for the development of sustainable local services/ environments.	Thank you for your comment. We agree and have, following stakeholder feedback, strengthened several of the recommendations related to early intervention and prevention. In the Aims and Principles section we have revised the wording to say 'the guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers'. We have also strengthened the wording and labelling of sections 1.3 on 'Early intervention and support for families and carers' and section '1.4 - Services in the community - prevention, early intervention and response' to reinforce the early intervention and prevention approach We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialists skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to faceface-to-face response within 4 hours if that is what is needed. The resource impact team did consider that the provision of intensive support during a crisis would likely incur costs to implement. They also said that implementing the guideline may also results in the following benefits and savings: lower rates of placement breakdown due to effective respire care and suitable housing. The unit cost per case of £31, 296 for a crisis resolution team for adults is taken from the unit costs of health and social care 2017. Lead commissioners will need to have 24/7 multi-disciplinary crisis support, and services should be developing in this way to meet the requirements of the Transforming Care agenda. The Guideline Ccommittee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.

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London Borough of Sutton Council	Short	19	5-8	1.4.8	Can this be further clarified is this 18 weeks to assessment process being started or this 18 weeks for introduction of behaviour support or 18 weeks for implementation of interventions?	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed.
London Borough of Sutton Council	Short	19	9-24	1.4.9	This seems unrealistic and potentially unhelpful as it is not clear what response would be expected to be provided during the 1 hour period over the phone. CTPLD's do not generally provide crisis services and it is unclear how this would be funded apart from taking further resource from services looking to provide emphasis on developing local capacity, reducing restrictive practices and improving the quality of these services through training. In most areas there are Emergency Duty Teams (EDT) it would probably be more helpful to provide additional training to these teams so that they could provide an initial contact, provide them a means to have access to existing advice, contact on who to speak to about agreeing any additional short term resource and guidance on how to gather information for professionals so they are ready to respond when they are back in the office. It would be helpful to gain more evidence for the efficacy of a resourced crisis response model for this client group and whether it leads to a reduced likelihood of initial admission or how it impacts the likelihood of future crisis/admissions.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. Thank you for your comment. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialists skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. The resource impact team did consider that the provision of intensive support during a crisis would likely incur costs to implement. They also said that implementing the guideline may also results in the following benefits and savings: lower rates of placement breakdown due to effective respire care and suitable housing. The unit cost per case of £31, 296 for a crisis resolution team for adults is taken from the unit costs of health and social care 2017. Lead commissioners will need to have 24/7 multi-disciplinary crisis support, and services should be developing in this way to meet the requirements of the Transforming Care agenda. The Guideline Committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
London Borough of Sutton Council	Short	20 21 3-11	21-27	1.5.1-1.5.2, 1.5.4-1.5.5	It is important that the person has a right to make decisions about where they want to live and to choose who they want to live with. It is clear that some people with the most challenging needs struggle to be able to tolerate sharing space with others, it may be essential that they live alone. Under the current housing situation in London Boroughs and funding arrangements and this may not be realistic or deliverable unless changes are made to housing policy for people with a learning disability. Where restrictions on accommodation and space exist for people in parts of the country (i.e. London) leading to smaller and more choice of potential environments. It is important that behaviour support guidelines are not used to justify the use of restrictive practices or the development of new institutional style living arrangements.	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life. It was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The cost effectiveness research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another or the optimum or maximum number of residents that could be specified that would be suitable for everyone, for this reason the reference to a specific number has been deleted. The Guideline Committee interpreted the available research evidence that congregating people together based on their behaviour that challenges and not based on their preferences or compatibility with other residents achieved worse outcomes, and cost effectiveness evidence that it was no more cost effective to group more than 6 people together. Evidence from expert witnesses together with their practice and experiential knowledge indicated that small numbers were more like an ordinary home for most people where people had a choice over who they lived with. The Guideline Committee agree that there was a lack of information on the most cost effective forms of accommodation and have developed a research recommendation to address this as a priority for future research.
Mencap	Short	10		1.1.12	Involving people in commissioning and service development Commissioners should also be involving people with a learning disability and families in the local community in shaping services and informing commissioning – for example by working with relevant self-advocacy and carers groups.	Thank you for your comment. The Guideline Committee agreed this is important and the reference to 'experts by experience' in this recommendation addresses this. This phrase is also defined in the 'Terms used in this guideline' as meaning people who use services and their family and carers.
Mencap	Short	10		1.1.8-1.1.11	Quality Assurance It would be helpful to include a statement that guides to an improved quality of life being the focus of what is provided. And as such the encouragement for	Thank you for your comment. Recommendation 1.1.10 now makes reference to 'restrictive interventions'. To take into account stakeholder consultation feedback, recommendation 1.1.10 has been updated to include reference to quality of life ratings, as suggested. It also now references quality checks by user organisations and quality review visits from community learning disability teams.

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					people to find measures of quality of life that show this (there could be a link to some of the tools). We would suggest the list of what 'evidence could include' includes reports on the use restrictions as well as use of restraint. It could refer to the measures identified in 'Positive and Safe' about reducing restrictions. This could enable both across provider and across LA comparisons, which would be useful for people looking to use a service. It would helpful to include in this section clear information about the quality assurance role of community teams. There is reference to the quality assurance role of community teams in the 'Developing community capacity' section, however, it is not clear whether this includes in house review and support, or if this is a data driven process – a mixture would be preferred.	
Mencap	Short	11	12&13	1.2.2	Involving people and their family members and carers We hear from families who have experienced the misuse of safeguarding powers against them, for example, following making a complaint about a service, the service has raised safeguarding concerns about the family. It is important the guideline says 'for example substantiated safeguarding concerns'. There should also be a note that where a person lacks capacity, any decision not to involve their family in decision-making should not be taken lightly as it is potentially unlawful (in line with the Mental Capacity Act).	Thank you for you for your comment. We have revised this recommendation to make clear that families should be involved when decisions are made in the person's best interest in line with the Mental Health Act 1983 After careful consideration, we have retained the text on safeguarding. We did not find research evidence on prevention of misuse of such powers, or people's views and experiences on the topic. However, in recommendation 1.3.5 we say that The named worker should advise family members and carers how to access: • local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.
Mencap	Short	12		1.2.9	Coordinating care We agree it is essential the person has a care coordinator. However, it is not clear what the criteria are to ensure this multidisciplinary approach. For example, who is entitled to a coordinator, how people will know this and what they can expect of them – it would be helpful to have more detail on this.	Thank you for your comment. We have revised the recommendation to make it clearer about how local authorities, clinical commissioning groups and service providers need to work in partnership to coordinate care and support.
Mencap	Short	15		1.3.1-1.3.4	Support for families and carers We welcome the focus on increased investment in families, including around information and training from specialist staff. It would be helpful to have a reference here regarding the need for local areas to offer support to families, including around building resilience, when children are at a very early age. There are a range of programmes targeted at parents of children with additional needs, such as Early Bird and a new programme developed by Dr Nick Gore at the Tizard Centre, University of Kent – E-PAtS (Early – Positive Approaches to Support) – which works with families and children at risk of behaviour that challenges. 'The aim of E-PAtS is to improve quality of life and reduce the risks of behaviour that challenges before a crisis is reached and to limiting the impact of such behaviour on children, families and professionals.' – ref Dr Nick Gore, Tizard Centre, University of Kent document on E-PAtS.	Thank you for your comment and support for the guideline. In the 'putting this guideline into practice' section we emphasise the need for local authorities and health services to provide comprehensive support for families including the need for 'ongoing training and support for their caring role from specialist services'. We say in recommendation 1.3.5 that training for families and carers needs to be in line with recommendations 1.7.1 and 1.7.2 in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Mencap	Short	15	16-23	1.3.3	Support for families and carers It would be helpful if this list included Advocacy and signposting to legal services when required.	Thank you for your comment. We have revised the recommendation to include reference to advocacy. The recommendation includes examples of different types of support and the Guideline Committee did not think that 'signposting to legal services' was a similar type of support.
Mencap	Short	16	9-19	1.3.5	Support for families and carers In relation to 'specialist behaviour support' - family members should be encouraged to access support early on before a crisis situation as this can help stop needs escalating and avoid a crisis situation. In law and policy there is a focus on 'prevention'.	Thank you for your comment. Following stakeholder feedback, we have strengthened several of the recommendations related to early intervention and prevention. In the Aims and Principles section we have revised the wording to say 'the guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers'. We have also strengthened the wording and labelling of sections 1.3 on 'Early intervention and support for families and carers' and section '1.4 - Services in the community- prevention, early intervention and response ' to reinforce the early intervention and prevention approach.

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Mencap	Short	18	8-13	1.4.4	Community learning disability teams They should work in a way that has a focus on early intervention and prevention of crisis.	Thank you for your comment. The Guideline Committee agree that it is important for community learning disability teams (CLDTs) to focus on early intervention and prevention of crisis. Following stakeholder feedback, we have strengthened several of the recommendations related to early intervention and prevention. We have emphasised it in the Aims and Principles. We have also strengthened the wording and labelling of sections 1.3 on 'Early intervention and support for families and carers' and section '1.4 - Services in the community- prevention, early intervention and response' to reinforce the importance of an early intervention and prevention approach.
Mencap	Short	19	11-24	1.4.9	Intensive behavioural support during a crisis It would be helpful to make clear that the response should include a person with the right expertise coming out and helping, where necessary ie not just someone giving guidance by phone. It would be helpful to include here that there should be flexible social care beds available which could be used if the person needs some time out from where they are living (to help avoid unnecessary admission to an inpatient unit). There could be a link here to the 'managing risks' section – which highlights shared responsibility between commissioner and provider.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or inpatient admission due to the lack of available specialist support in the community.
Mencap	Short	20&21		1.5.1 to 1.5.7	Housing It is important there are professionals with the right expertise around housing to support individuals and families in relation to getting the right housing for the individual, including where someone needs a complex bespoke package of care. Families should not have to drive the housing element – it is part of the development of a person's package in the community.	Thank you for your comment. The Guideline Committee agreed that the level of detail in this area of the recommendations is sufficient. Recommendations 1.2.10 to 1.2.13 ensures that there is a single named practitioner to co-ordinate a person's care and that he or she take into account the expertise brought by all members of that person's network. Recommendation 1.5.4 covers the things to consider when helping adults with a learning disability and behaviour that challenges choose where to live.
Mencap	Short	21	12-19	1.5.6	Housing In relation to people being offered housing outside their local community – it should make clear that robust information needs to be given to people around this, detailing other options and possible outcomes. We know that the time – whether specified or not – can be greatly lengthened by sectioning. We are concerned that giving families a 'specified time' provides a false sense of security. Families and people with a learning disability need to be fully informed of all possibilities and should be signposted to advice and support.	Thank you for your comment. Providing information on options is covered in recommendation 1.5.4.
Mencap	Short	22,23,24		1.6.1-1.6.11	Services for children and young people 'Research and clinical practice suggests that the risks of behaviour that challenges can be reduced by better recognising and meeting the needs of people with learning disabilities. Yet far too often this support is only provided at a late stage when individuals and families are at a crisis point.' –ref Dr Nick Gore, Tizard Centre, University of Kent document on E-PAtS It is vital that the NICE guidance emphasises the importance of provision of early help services to children with a learning disability to help prevent challenging behaviour emerging and becoming ingrained during childhood. 'Without intervention, behaviours that challenge often continue into adulthood, presenting further difficulties for individuals, families and services.' –ref Dr Nick Gore, Tizard Centre, University of Kent document on E-PAtS We would like to see the guidance being more explicit about the value of early intervention in helping to prevent challenging behaviour. For example, we would like to see the guidance setting out that, in fulfilling the joint commissioning duties under the Children and Families Act, local areas should have a particular focus on planning for and providing early interventions for children with a learning disability to help prevent challenging behaviour	Thank you for your comment. We have strengthened several of the recommendations related to early intervention and prevention. In the aims and principles section we have revised the wording to say 'the guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers'. We have also strengthened the wording and labelling of sections 1.3 on 'support for families and carers' and section '1.4 - services in the community' to reinforce the early intervention and prevention approach. Section 1.6 notes that interventions and support should be provided in line with the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).

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					emerging and becoming ingrained during childhood. This should include making sure there is careful analysis of the population of children with learning disability in the local areas to ensure provision can meet local need, processes to assess their need (and potential need) for support, and pathways of support to ensure they get early help. For example, the provision of speech and language therapy to aid communication; the effective and timely provision of short breaks to help ensure family wellbeing is not impacted by caring responsibilities; and as referenced in our comments regarding the support for families section, the availability of family support programmes. The guidance could refer to the service model from the Transforming Care programme here, which identifies early intervention/ early support, and support and skills training for parents as part of a regional/community response to better services for families of children with a learning disability.	
Mencap	Short	25	14-17	1.8.1	Making the right use of inpatient services It would be helpful to include here, that 'all possibilities for doing so have been considered and exhausted, including bespoke packages of care in the community. There must be a clear written rationale, detailing all this.'	Thank you for your comment. The Guideline Committee agree that it is essential to be clear that all alternatives have been explored (and the process documented) before an individual is admitted as an inpatient. After careful consideration, we think that this recommendation adequately covers these issues. The importance of personalised, community based support is emphasised throughout the guideline. See for example, the 'Aims and Principles' section.
Mencap	Short	25	21&22	1.8.2	It is important that the practitioner has expertise around bespoke packages of care in the community for people with a learning disability and behaviour that challenges so they understand creative community solutions.	Thank you for your comment. After careful consideration, we think that this principle is adequately covered in the recommendation. In recommendation 1.8.9 we say that inpatient practitioners should work with community learning disability teams to develop a discharge plan as soon as possible. In this recommendation the expertise is shared between the inpatient practitioners and the community learning disability teams who by working together can establish what community services need to be in place for the person to enable discharge.
Mencap	Short	26	1-2	1.8.3	Individuals and families should also get a clear written rationale for why inpatient admission is necessary and why a bespoke package of care in the community is not appropriate at this time.	Thank you for your comment. The wording of the recommendations follow from other recommendations on building capacity in the community which, if implemented, would mean that admission to hospital will only be based on clinical need and not because of a lack of more appropriate services in the community. Recommendation 1.8.3 states that information about admission should be given in an accessible format, which would include being in a written format if that is what the person and their family prefer. Recommendation 1.8.2 states that all other options should be considered before admission, and cross-references to guidance on the Care and Treatment Review and Care, Education and Treatment Review processes.
Mencap	Short	26	28-30	1.8.10	Planning and review to support discharge	Thank you for your comment. The Guideline Committee considered the importance of planning for discharge straight away. The frecommendations at the start of section are about exploring alternatives to inpatient admission, only once these alternatives have been exhausted do we have recommendations on planning for discharge once admitted in the Planning and review to support discharge section.
Mencap	Short	26	9-11	1.8.6	This should include a recognition that funding will be needed to support families to visit in line with the person's needs and rights.	Thank you for your comment. The wording of the recommendations follow on from other recommendations on building capacity in the community which, if implemented, would mean that admission to hospital will only be based on clinical need and not because of a lack more appropriate services in the community. Where inpatient service are appropriate and necessary, and after all other options have bene considered, the Guideline Committee considered that people should be placed as close to home as possible. There is no current automatic entitlement to reimbursements of travel costs for visiting people in inpatient hospitals unless in receipt of qualifying benefits. NICE guidance focuses on 'what works' and therefore it is beyond the remit of NICE guidance to make recommendations about funding of local authority reimbursements.
Mencap	Short	6		Legal duties	Relevant legislation includes the Human Rights Act 1998.	Thank you for your comment. We have revised the list of relevant legal duties and guidance to include the Human Rights Act 1998 as you suggest.
Mencap	Short	9		1.1.7	Managing risk	Thank you for your comment and support for this recommendation. We think the description is sufficient as the organisations involved will vary depending upon the specific situation and context.

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					We welcome the focus on shared responsibility between the commissioner and provider. It would be helpful to have a clearer link here to the 'Intensive behavioural support during a crisis' section.	
Mencap	Short	General		general	We welcome the recommendation that each area has a lead commissioner that has knowledge and expertise in learning disability and behaviour that challenges and that they commission services for this group of individuals across both children and adult's services to ensure a lifelong, joined up approach. We welcome the focus on investment in families. We welcome the focus on person centred care. Whilst there are some references to positive behaviour support we think it would be helpful to have more focus on this approach as a way of working with people who display behaviour that challenges. This would incorporate person centred thinking as PBS is person centred in it values but would elevate the approach of PBS to one that is commissioned for all services for people who display behaviour that challenges, this may also mean that there was greater emphasis on skills development (for people using services). We would like to see more focus in the guideline on early intervention to help prevent behaviour that challenges emerging and becoming ingrained in childhood.	Thank you for your comment. Several recommendations have been revised to place greater emphasis on supporting families, and on prevention and early intervention to prevent crisis, specifically, the Aims and Principles of the guidelines, section 1.4 heading has been changed to emphasise that community services should be Services in the community – prevention, early intervention and response. Recommendation 1.4.11 has been revised to state that when reducing the level of support from more intensive services, lessons should be learned to inform future early intervention and prevention services and support crisis plans.
Mencap	Short	General		general	One area we think could be developed more in the guidance is support for those supporting people with a learning disability and behaviour that challenges (including families and support workers) and ensuring their wellbeing. An important part of providing good support is an understanding that supporting people who display behaviour that challenges is sometimes emotionally demanding. It would be helpful if this guidance could describe what the support offered to families and/or support workers should or could look like. This could be anything from ensuring that in commissioning services there is the recognition that those supporting people with a learning disability who display challenging behaviour may need support to debrief following incidents, right through to the need to offer specialist services that those supporting people are able to access.	Thank you for your comment. Recommendation 1.9.1 about staff skills and knowledge refers to the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11 for recommendations on how best to support staff in their role. A hyperlink is included for people who want more detail. We agree that there should be a greater emphasis on supporting people who do most of the day to day work of caring and that families should be supported in accessing specialist support when they need it. We have revised recommendation 1.4.8 to say that there should be an individual assessment of each person's need and risk, and taking in to account the benefit of early intervention. We have revised recommendation 1.4.9 to say that commissioners should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support. In recommendation 1.3.3 we have said that families and carers should have access to other forms of support, such as: • peer support • parent and carer groups • email support • individual phone and in-person face-to-face support • family networks • advocacy • managed email networks (a shared discussion forum) • social media groups
National Development Team for Inclusion	Short	10	12	1.1.8	Should also include seclusion, harm to selves and from others, use of PRN	Thank you for your comment. The wording has been edited to 'reports on use of restrictive interventions, including medication'.
National Developmen	Short	11	11	1.2.2	If family and friends are not involved, the discussion should include an advocate who knows the person well	Thank you for your comment. We have revised the wording of this recommendation (1.2.4) as follows: 'Involve children, young people and adults' families, friends, carers or advocate if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental

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t Team for Inclusion						Capacity Act 2005. This should be done unless there is a compelling reason not to (for example if there are safeguarding concerns)'.
National Development Team for Inclusion	Short	12	8	1.2.6	Make reference to the 5 good communication standards here and the Accessible Information Standard	Thank you for your comment. We have revised this recommendation to include reference to the Accessible Information Standard. We will also pass this information to our resource endorsement team. More information on endorsement can be found here: (https://www.nice.org.uk/about/what-we-do/into-practice/endorsement)
National Development Team for Inclusion	Short	14	17	1.2.17	Should read – how much control they can have over how the money is spent – takes into account that some people want less control than others – depending on how actively they want to be involved	Thank you for your comment. We agree that different people want different levels of control over budgets. Your point about including reference to 'how much control they can have over how the money is spent' is included in the second bullet of 1.2.20.
National Development Team for Inclusion	Short	19	8	1.4.8	18 weeks still seems a very long time	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems and to provide a face to face response within 4 hours if that is what is needed. We have revised Recommendation 1.4.9 which now states that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support.
National Development Team for Inclusion	Short	22	4	1.5.8	I think this needs to be more specific and include routine health checks such as eye and hearing tests and visits to the dentist as well as annual health checks and participation in screening programmes	Thank you for your comment. The Committee agreed that the level of detail in this recommendation was sufficient. This is on the basis that the guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation. In addition, NICE guidelines aim not to duplicate guidance which is provided elsewhere and The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) includes a recommendation (1.2.1) about offering annual health checks.
National Development Team for Inclusion	Short	22	5	1.5.8	Should say, maintain and develop friends, relationships and social/community networks	Thank you for your comment. We have revised this recommendation (now recommendation 1.2.23) as you suggested.
National Development Team for Inclusion	Short	22-23		1.5.8-1.6.7	Should say, maximise preparing for adulthood outcomes (as in the code of practice) for children and young people identified in their EHC plans. (Employment, friends and relationships and community, independent living and good health)	Thank you for your comment. We have added employment and pre-employment opportunities to the list (now recommendation 1.2.23),as well as maintain relationships, making friends and social networks, and maintaining health and wellbeing. The guideline discussed the concept of independent living and opted for a definition that favoured living as one chooses and cautions that promoting independent living could suggest a withdrawal of support.
National Development Team for Inclusion	Short	23	6	1.6.4	Reviews should include the young person too.	Thank you for your comment. The recommendation has been edited accordingly.
National Development Team for Inclusion	Short	24	10	1.6.9	And ensure that they continue to be supported to meet the outcomes identified in their EHC plan	Thank you for your comment. This recommendation has been edited accordingly.
National Development Team for Inclusion	Short	24	11	1.6.10	Should say person centred reviews	Thank you for your comment. The Guideline Committee did not think that 'person centred' needed to be added to this specific recommendation. We agree that the care pathway, plan and reviews should be person-centred and we have made this approach central to the whole guideline. This is reflected in the Aims and Principles, throughout section 1.2 and in recommendations 1.1.2, 1.1.7 and 1.5.1 of the guideline.

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						We found that there is little published research about what configurations of services and resources provide the best person-centred support for people with a learning disability and behaviour that challenges, and their families and carers, so the committee has made a research recommendation in this area.
National Development Team for Inclusion	Short	24	22	1.7	Should say Short Breaks instead of Respite Care	Thank you for your comment. The recommendations now refer to 'Short' breaks services' rather than 'respite care.'
National Development Team for Inclusion	Short	25	4	1.7.2	Should say, support delivery of the outcomes agreed in the EHC plan (for example, provide work experience or independent travel training)	Thank you for your comment. The recommendation specifies that respite care should support the delivery of the Education, Health and Care Plan. This may therefore include work experience and independent travel training.
National Development Team for Inclusion	Short	25	9	1.7.2	Assumes that the short break will be building based and may not be. Young people could use a personal budget to support PA involvement so that they can use community based facilities such as theatre, cinema, sports and leisure	Thank you for your comment. Recommendations 1.7.1 and 1.7.2 have been amended to specify a range of short breaks options.
National Development Team for Inclusion	Short	26	13	1.8.7	Include disabled children's practitioners and transition practitioners for those under 18 (may be up to 25)	Thank you for your comment. The Guideline Committee agree that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff.
National Development Team for Inclusion	Short	26	16	1.8.7	Worth specifying that social workers should remain in contact, and the individuals case should remain open to the social worker while the individual is in A&T. Should also note, that where possible and appropriate the individual's placement should be kept for them.	Thank you for your comment. Recommendation 1.8.7 implies that the individual's case should remain open, so that his or her social worker can continue to support them.
National Development Team for Inclusion	Short	26	23	1.8.9	And children's teams (link to Nice Transition guidance)	Thank you for your comment. As this section is relevant to children, young people and adults we have not referenced the NICE guidelines on Transition between inpatient hospital settings and community as the population focus of the guideline was adults only. The guideline on Transition for children guidelines focus is from children to adult services. In this recommendation the community learning disability teams includes those for both adults and children's services.
National Development Team for Inclusion	Short	9	11	1.1.5	Think this should read 'is based on' rather than 'enables'	Thank you for your comment. We have revised this recommendation to read: based on local need.
National Development Team for Inclusion	Short	9	27	1.1.7	The risk sharing should also include community team members and psychiatrists when appropriate	Thank you for your comment. This has been edited to include reference to working with other organisations, to reflect that the people involved will vary depending upon the specific situation and context.
National Development Team for Inclusion	Short	9	35	1.1.6 - 1.1.7	Commissioners should develop good relationships with providers so that honest conversations can happen early if there are difficulties. Services should be commissioned in a way that is respectful of individuals, and not commissioned on the basis of cost alone[11.1.6/1.1.7? (Main table refers to line 35 – as there isn't one am assuming this to be 25 which straddles these two recs). So have cross referenced to these two recs.]	Thank you for your comment and support for this recommendation. The committee agreed on the importance of provider involvement in service planning, which is referenced in recommendations 1.1.10, 1.1.13, 1.2.10. 1.2.13 and 1.2.19.
Newlife	short	10	16	1.1.9	Children should not be discharged home in to the care of their families without a full assessment of the child and family's equipment needs. This includes equipment to ensure the safety of all members of the family. It is simply not	Thank you for your comment. The reference to 'detailed assessments' within this recommendation seeks to encompass a wide range of issues, such as those you raise. There are also a series of recommendations on discharge (1.8.9-1.8.13),with 1.8.10 making specific reference to children and young people.

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					good enough to discharge children home and then start the assessment process for keeping them safe.	
Newlife	short	15	1	1.3.5	Newlife would request the inclusion of Community Equipment within the list of specialist services.	Thank you for your comment. Community equipment is covered by the term 'community resources' in this recommendation.
Newlife	short	16	7	1.3.5	Newlife would request the inclusion of Community Equipment within the list of information provided to families.	Thank you for your comment. Community equipment is covered by the term 'community resources' in this recommendation.
Newlife	short	24	22	1.7	Inclusion within this should be the provision of equipment to enable to children to access respite care. Newlife routinely receives requests to funding specialist items such as beds, wheelchairs and hoists to allow children to access Local Authority funded respite.	Thank you for your comment. The committee agree that children and young people should be supported to access respite care. After careful consideration, we think that this is covered adequately in this recommendation, for example, when referring to tailored support. Community equipment is covered by the term 'community resources' in this recommendation.
Newlife	Short	7 and 12	1 22	1.2.1 and background	"People have the right to be involved in discussions and make informed decisions about their care". From surveying our families, we know that 52% feel that their child's health and wellbeing is detrimentally affected by delays in accessing professional assessments. Newlife wholly supports the right for families to be involved in discussions about their child's care but our experience is that a lack of qualified professionals in the community will mean that meeting this objective will require careful financial planning.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommendations made by the Guideline Committee.
Newlife	short	7	16	Aims and principles	Newlife provides the only national "emergency equipment loan service" to support families in need of essential equipment (such as safe beds) when they hit crisis point. We welcome the focus on early intervention and preventing crisis.	Thank you for your comment and support for this guideline. The Guideline Committee agrees that is important to emphasise supporting families, prevention and early intervention to prevent crisis.
Newlife	short	8	14	1.1.3	In order to plan effective budgets for these children it is essential to understand the level of need locally. Newlife would strongly recommend the adoption of the Family Resource Survey identified that 7% of the child population have a disability, this equates to almost 1 million children nationally.	Thank you for your comment. There are a number of tools and methods available for service planning at the local level. The wording of recommendation 1.1.8 seeks to provide flexibility in local-level implementation while also being clear that data on local need should be collated and used to inform planning. We will also pass this information to NICE's resource endorsement team. More information on endorsement can be found here
Newlife	short	8	4	1.1.1	Q1 – Designation of a single commissioner will present a significant challenge to health, social care and education unless there are fully embedded joint funding and commission arrangements. This target (if used alongside joint holistic assessments) is likely to have a very positive impact on families with children with challenging behaviour. This is particularly pertinent to those in need of equipment the crosses the divide between health and social care.	Thank you for your comment. Recommendation 1.1.2 has been amended to clarify that the lead commissioner should oversee joined up commissioning arrangements. Recommendation 1.1.4 relates to pooled budgets.
Newlife	short	9	1	1.1.16 (population/ prevalence)	In order to plan effective budgets for these children it is essential to understand the level of need locally. Newlife would strongly recommend the adoption of the Family Resource Survey identified that 7% of the child population have a disability, this equates to almost 1 million children nationally. Newlife	Thank you for your comment. There are a number of tools and methods available for service planning at the local level. The wording of recommendation 1.1.8 seeks to provide flexibility in local-level implementation while also being clear that data on local need should be collated and used to inform planning.
Newlife	short	9	2	1.1.5	Local Authorities have a legal duty to keep and maintain Child Disability Registers. Promotion and use of these Registers provides an opportunity to commissioners to better plan for population need. From our research, we know that 82% of disabled children are not included in these Local Registers.	Thank you for your comment. We have revised recommendation 1.1.8 to included Child Disability Registers.
NHS England	Short	General		general	These guidelines support and are compatible with what NHSE set out in the Service Model and Model service specs and we are supportive of the draft guidance . Reinforcing the need for example PBS, CTR and CETR is positive in embedding these positive actions in the system going forward The idea of a lead commissioner across ages and agencies is a new concept (though aligned to TCP SROs). The named worker role reflects the role named Care and support navigator and the Named Social Worker role as	Thank you for your comment and support for the guideline. The Guideline Committee agree that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff. Similarly, we have clarified that the lead commissioner is a role that will have strategic oversight across ages, and take a whole life approach to planning.

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					well as reinforce our direction about ensuring local community maintains a responsibility for person when placed out-of-area.	
Northumberland, Tyne and Wear NHS Trust	short	11	24	1.2.3	Rather than helping as soon as problems emerge should this include prevention of problems	Thank you for your comment. Several recommendations have been revised to place greater emphasis on supporting families, and on prevention and early intervention to prevent crisis, specifically, the Aims and Principles of the guidelines. Section 1.4 heading has been changed to emphasise that community services should be Services in the community – prevention, early intervention and response. Recommendation 1.4.11 has been revised to state that when reducing the level of support from more intensive services, lessons should be learned to inform future early intervention and prevention services and support crisis plans.
Northumberland, Tyne and Wear NHS Trust	short	15	8	1.3.1	The guidance suggests that specialist services should be sought including 'behaviour analysis and positive behaviour support'; however, these are potentially beneficial approaches not services.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Northumberland, Tyne and Wear NHS Trust	short	17	11	1.4.3	There's a list of people who can offer support this is a mix of healthcare professions and competencies (e.g. forensic learning disability; behaviour therapist)	Thank you for your comment. We have revised the recommendation by removing the list of professionals as this was too prescriptive. We have added in this recommendation on what should be achieved by saying that this could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.
Northumberland, Tyne and Wear NHS Trust	short	28	1	1.9.3	'Behaviour support specialists' are referred to. This is not an acknowledged professional title and in the glossary an example of behaviour support specialist provided is a behaviour analyst which is also not an acknowledged professional title in the UK. There is also very limited evidence to support the effectiveness of behaviour analysts (1 study in the long version mentions behaviour analysts and does not demonstrate the effectiveness of the role). This should be reworded to remove the terms Behaviour Support Specialist and Behaviour Analyst from the document as they are potentially unregulated and could place people with learning disabilities at risk as a result.	Thank you for your comment. We have removed the term from recommendations when used as a profession title. We have kept the term "behaviour support" to be a generic term for behavioural interventions that are in line with the evidence-based interventions in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Northumberland, Tyne and Wear NHS Trust	Short	5	4	Background	The comment "In particular this aims to shift emphasis from inpatient care in mental health hospitals, towards care provided by general and specialist services in the community." In response to Winterbourne View is odd as at the time of Winterbourne View a very small proportion of people with learning disabilities received care within hospitals as the vast majority of this provision had been closed in the preceding decades and replaced with community based provision. This context risks people continuing the misplaced focus on reducing beds as the most important target whilst missing the functional reasons for abuse.	Thank you for your comment. We have revised the text to be in line with the aims of transforming care, although a reduction on the reliance on inpatient services would be the likely outcomes, the Aims and Principles now read: The guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers. This should reduce the need for people to move away for care and treatment
Northwest Boroughs NHS Healthcare Foundation Trust	Full	11		1.1.8	1.1.8 Who will review the propose quality indicators? could this be specified? could qualitative feedback from service-users and families be a form of feedback?	Thank you for your comment. To take into account stakeholder consultation feedback, this recommendation has been updated to include reference to quality of life ratings, as suggested. It also now references quality checks by user organisations and quality review visits from community learning disability teams.
Northwest Boroughs NHS Healthcare	Full	12		1.2	1.2 A huge issue at times is the lack of past records/history on a person who has moved. Access to health and social services records is often difficult, and people often do not move with their information. As such it can be as if a	Thank you for your comment. Recommendation 1.5.8 refers to arrangements for when people move outside their local area.

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Foundation Trust					person has no history and makes it very difficult when attempting formulations. Northwest Boroughs NHS Healthcare Foundation Trust	
Northwest Boroughs NHS Healthcare Foundation Trust	Full	12		1.2.3	1.2.3 Care should be tailored around needs and not the other way around. It is not unusual to find service-users having to go to bed or leave an activity early due to staff rotas.	Thank you for your comment. This recommendation aims to uphold the principle about care being designed around the needs of the individual.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	13		1.2.10	1.2.10 'Regular meetings' is vague. How do these types of meetings link with annual reviews? and are they similar to Person Centred plans?	Thank you for your comment. The frequency of meetings has not been specified as it may differ for each person.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	13		1.2.4	1.2.4 Staff training in the MCA is needed	Thank you for your comment. While specific training courses are out of scope for this guideline we understand that health and social care providers must comply with the Mental Capacity Act and Care Quality Commission requirements, and promote human rights in their practice. There is also a NICE guideline (NICE in development on Decision making and mental capacity.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	13		1.2.6 and 1.2.7	1.2.6 and 1.2.7 The importance of speech therapy input should be highlighted/recommended here	Thank you for your comment. The Guideline Committee agree about highlighting the importance of the need for access to speech and language specialist input. This is reflected in recommendation 1.2.7.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	13		1.2.8	1.2.8 Could an example of when an advocate is useful be provided?	Thank you for your comment. The Guideline Committee gave careful consideration to your comment, but did not think an example was needed in this recommendation. An example is already included in recommendation 1.8.3 in relation to when there is a possibility that someone will be admitted to hospital.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	13		1.2.9	1.2.9 Social workers are increasingly not part of LD teams. How do we determine who is the named worker, particularly if services are fragmented and operating under different organisations and procedures?	Thank you for your comment. We have revised the recommendation to make it clearer about how local authorities, clinical commissioning groups and service providers need to work in partnership to coordinate care and support and to provide additional examples of the type of practitioner that could provide the care coordinator role.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	14		1.2.11	1.2.11 Should it be specified who takes the lead on care plans?	Thank you for your comment. We specify which organisations are responsible for developing care and support plans in recommendation 1.2.14.

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Northwest Boroughs NHS Healthcare Foundation Trust	Full	14		1.2.11	1.2.11 What does a 'positive approach to risk management' mean? this needs specifying	Thank you for your comment. A positive approach to managing risk means managing risks to maximise people's choice and control over their services and support. We provide further clarification about what this means in recommendation 1.1.10, Managing risk.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	14		1.2.12	1.2.12 Who takes the lead on PBS plans? clear accountability would be helpful if possible	Thank you for your comment. We specify which organisations are responsible for developing care and support plans in recommendation 1.2.14.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	14		1.2.13	1.2.13 Matching staff to the person with an LD- what staff? what does this mean? more detail/clarity needed	Thank you for your comment. This recommendation is directed at service providers and agencies that commission services and that all staff who work with people with a learning disability and behaviour that challenges should have the skills necessary to work with that particular person and that service providers and commissioners need to give consideration to the specific needs and preferences of that person. More information on the skills and values of staff are in section 1.9. The committee are aware that this may not be possible in all instances but thought it important to recommend and highlight best practice, based on the research evidence. They consider the recommendation to be aspirational but achievable.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	15		1.2.16	1.2.16 Personal budgets-sometimes it is inappropriate to offer this due to concerns around vulnerability/family dynamics/abilities	Thank you for your comment. We have revised recommendation 1.2.19 to read that local authorities and clinical commissioning groups need to 'ensure that a range of funding arrangements are available, including direct payments, personal budgets or individual service funds, depending on children, young people and adults' needs and preferences'. Think about using integrated personal commissioning where it is available We agree that the local authority is obliged to offer these where people are eligible and it is appropriate.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	16		1.3	1.3 Service-users also need to know about their rights and how they can raise safeguardings	Thank you for your comment. This is covered in the last bullet point of recommendation 1.3.5.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	16		1.3.1	1.3.1 This list does not seem comprehensive	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	16		1.3.1	1.3.1 Should read 'staff trained in PBS?'	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.

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Northwest Boroughs NHS Healthcare Foundation Trust	Full	16		1.3.3	1.3.3 Email support – who would provide this?	Thank you for your comment. Community learning disability teams or other services in the community would provide email support.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	19		1.4.6	1.4.6 It is not always appropriate to divert people from the criminal justice system	Thank you for your comment. We have emphasised in the recommendation that community learning disability teams should maintain good communication links with the police and liaison and diversion teams. We hope that if communication is both ways that community learning disability teams (CLDTs) could advise the Criminal Justice System (CJS) when they think it would be more appropriate for a person to be in the CJS.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	20		1.4.9	1.4.9 Who should provide the crisis support, and where does the funding come from?	Thank you for your comment. This is covered at the beginning of section 1.4 and 1.1 in the guideline. The lead commissioner, jointly designated by local authorities and clinical commissioning groups is responsible for commissioning services in the community for people with a learning disability and behaviour that challenges (including for people in contact with, or at risk of contact with, the criminal justice system), including crisis support. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	20		1.4.9	1.4.9 Should read 'people should stay in their own home where appropriate' as it is not always	Thank you for your comment. The recommendation covers providing a personalised approach, which could include taking into account the impact of living at home.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	20		1.4.9	1.4.9 What about the role of the police and emergency services? this is needed at times. More on sharing of info needed- eg ensure plans for people on risk register are shared with appropriate parties	Thank you for your comment. We agree that health and social care services need to work with other related services. In recommendation 1.1.8 we say that planning for services locally can make use of records of referrals from Liaison and diversion teams. In recommendation 1.4.6 we say that community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that: • they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable • people who need support can be diverted from the criminal justice service to community learning disability teams. We hope that the implementation of the recommendations on prevention, early intervention, supporting families and out of hours crisis triage and response will reduce the inappropriate involvement of criminal justice and inpatient admission because of the lack of local community supports.
Northwest Boroughs	Full	9			1.1.5 When discussing planning of services, there is no mention of involving the service user and/or family, or of LD teams.	Thank you for your comment. We have revised the recommendation to say that identification of needs and service development should be co-produced.

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NHS Healthcare Foundation Trust						
Northwest Boroughs NHS Healthcare Foundation Trust	Full	General			The term challenging behaviour is used inconsistently e.g. challenging behaviour, behaviour that challenges	Thank you for your comment. All uses of the term in the guideline have been checked and amended to 'behaviour that challenges'. However, we do make reference to another NICE guideline which is entitled (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11)
Northwest Boroughs NHS Healthcare Foundation Trust	Full	general		General	What about the role of mental health teams	Thank you for your comment. Recommendation 1.4.3 states that community learning disability teams should ensure that people should have access to a range of specialist support services to meet their needs, including their mental health needs. The population in scope for this services guideline is people with a learning disability and who display behaviour that challenges, and people may or may not also have a mental health need which we address in this recommendation. For people with learning disabilities and mental health needs (but not behaviour that challenges) there is another NICE guideline (Mental health problems in people with learning disabilities: prevention, assessment and management. NICE guideline (NG54).
Northwest Boroughs NHS Healthcare Foundation Trust	Full	general	General		More detail needed on essential training for carers and procedures for what to do when carers skills and approaches are lacking, and whose responsibility this is. Currently it is very common for providers to be unable to deliver the quality of service promised, and the case goes into crisis resulting in a move/admission. CLDT efforts to prevent this are all too often unsuccessful.	Thank you for your comment. The Guideline Committee recognised the importance of good quality services in preventing crisis, and recommendations 1.1.10 to 1.1.14 refer to quality assurance of services.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	general	General		Services have two key challenges: 1) determining who is accountable for what, causing numerous discussions and clients being 'passed back and forth' .this applies to confusion around generic versus LD services (community and inpatient) and within LD services. and 2) lack of high quality care services –low paid, undertrained care staff with high turnover and lack of skill in behavioural approaches	Thank you for your comment. We hope the recommendations in this guideline will support people in addressing these issues, in particular in providing services based on need rather than on funding streams. For example, the guideline recommends a lead commissioner across health and social care (recommendation 1.1.1) and pooled budgets (1.1.4). Section 1.9 makes recommendations about staff skills and values.
Northwest Boroughs NHS Healthcare Foundation Trust	Full	general	General		The Auden PBS Grp reviewed the guidance and made the following notes from a Secure In Patient LSU Service perspective: SALT access is vital to ensure effective communication Care Co-ordinator responsibility for attending planned CTR,s etc Agreed Pathways across services is vital (Greenlight toolkit etc) PBS accredited model to be agreed ? BILD and sufficient staff trained in its application Consider appointing Behavioural Nurse Specialists to support PBS Consider Specialist Street Triage Services / Diversion Panels to be considered Service criteria to be reviewed as a priority PBS Pathway to be developed	Thank you for your comment. Reference to speech and language therapy is now included in recommendation 1.2.7. We have also recommended a named worker (recommendation 1.2.10) – this could be the care co-ordinator for people who have one. Recommendation 1.1.9 relates to having an agreed care pathway. Recommendations 1.9.2 and 1.9.3 refer to the Positive behaviour support competence framework. P, and recommends that staff should meet the requirements of the framework. With regard to behavioural nurse specialists and diversion panels, we did not find any evidence on these topics.
Northwest Boroughs NHS Healthcare	Full	general	General	1.4.9	Who and how should out of hours support be provided	Thank you for your comment. We have revised recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems and to provide a face to face response within 4 hours if that is

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Foundation Trust						what is needed. We have revised Recommendation 1.4.9 which now reads that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support.
Nottinghamshire Healthcare NHS Foundation Trust	Short	12	1.2.10	1.2.10	We welcome this emphasis on the local authority becoming involved in the care co-ordination role. Over the past few years some local authorities have pulled away from this role.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommendations made by the Guideline Committee.
Nottinghamshire Healthcare NHS Foundation Trust	Short	15		1.3.1	Psychiatrists have a lot to contribute in this area (not just medication prescription), so need to be included in the list of professionals mentioned in this section	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Nottinghamshire Healthcare NHS Foundation Trust	Short	20		1.4.12	Forensic community learning disability teams should not be limited to supporting people with an intellectual disability who are subject to a forensic community rehabilitation order or a community treatment order; they should also support those with risky challenging behaviour even if not yet within the legal system (sometimes risky behaviour might be ignored/tolerated by others due to the person's intellectual disabilities).	Thank you for your comment. We have revised recommendations 1.4.12 and 1.4.6 to make it clearer that forensic services need to address the needs of people at risk of contact with the Criminal Justice System or at risk of developing offending behaviours.
Nottinghamshire Healthcare NHS Foundation Trust	Short	General		general	Consider substituting 'intellectual disabilities' for 'learning disabilities'	Thank you for your comment and suggestion. We acknowledge that there are different terms used, over time and geographical area. To avoid confusion, we have used the term that is currently used in the literature and that has been used in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Peer reviewer (PB)	Short	10	11		Very good to see "stability of placements" – also school attendance?	Thank you for your comment. We have added reference to participation in education by children and young people to this recommendation.
Peer reviewer (PB)	Short	10	12		Also "overuse of sedative medication" and isolation?	Thank you for your comment. We have added 'including use of medication' to the bullet point on restrictive interventions. We would consider use of isolation as part of restrictive interventions.
Peer reviewer (PB)	Short	10	2		Add "reduction in behaviour that challenges: frequency and duration"? or similar	Thank you for your comment. We have amended the recommendation accordingly.
Peer reviewer (PB)	Short	11	28		Staff should assume capacity - MCA	Thank you for your comment. The Guideline Committee also took this view, and this is reflected in the wording of the recommendation.
Peer reviewer (PB)	Short	12	22		Could this be a teacher or health professional (Health Visitor/ School Nurse) – unlikely to be a Social Worker for children and young people – reads as adult centric?	Thank you for your comment. This recommendation has been amended to refer to a social worker from a disabled children's team as an example.
Peer reviewer (PB)	Short	12	25		Include reference to EHCP for children – bearing in mind not all children/ young people in this cohort will have EHCPs	Thank you for your comment. The Education, Health and Care planning process has been added as an example in the recommendation.

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Peer reviewer (PB)	Short	12	3		Suggests that children have to be Gillick competent to be included in decisions about their care. All children and young people should be included regardless of Gillick competence	Thank you for your comment. The wording of the recommendation is intended to reflect that practitioners should work in partnership with all children and young people.
Peer reviewer (PB)	Short	13	12		Adult centric – also implies CLDT takes lead – could also be CAMHs, YOT, SEND, CMHT etc. supported by CLDT?	Thank you for your comment. This recommendation has been amended to refer to children's services, giving CAMHS learning disability services as an example.
Peer reviewer (PB)	Short	13	2		Also disabled children's teams/ schools etc	Thank you for your comment. This recommendation has been amended to refer to children's services.
Peer reviewer (PB)	Short	15	5		What would be the role/ function of psychology? Could this be undertaken by other therapists or a nurse-led service? Speech and language therapy – support with communication? Occupational therapy – sensory integration etc.?	Thank you for your comment. This recommendation has been amended to be based on the types of needs people may have – as you have pointed out, these may be met by a range of services.
Peer reviewer (PB)	Short	16	22		Role of Lead commissioner – is this a specific set of functions? Is this a single commissioner. Should the lead commissioner read "responsible commissioner"?	Thank you for your comment. This refers to the lead commissioner role set out in recommendations 1.1.1 and 1.1.2.
Peer reviewer (PB)	Short	16	9		"advise family members or carers about their right to..." Is there a right to these services/ functions? And is there a corresponding local duty to provide?	Thank you for your comment. This recommendation has been phrased in terms of how to access services.
Peer reviewer (PB)	Short	17	18		"acting through the single commissioner" – what does acting through mean in this context? Oversight?	Thank you for your comment. This wording is intended to convey that the lead commissioner would undertake these actions on behalf of the local authority and clinical commissioning group (CCG). It has been worded in this way in recognition of the fact that not all areas have, or will have, a lead commissioner – in which case the responsibility for the recommendations lies with the local authority and CCG.
Peer reviewer (PB)	Short	18	16		Not just "refer"... co-work, lead where appropriate (asking support from forensic teams). Include Youth Justice/ Youth Offending – examples adult centric	Thank you for your comment. The recommendation has been amended as you advise.
Peer reviewer (PB)	Short	19	17		Respond in one hour? What will this response include? Will this offer be available 24/7 52 weeks?	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised recommendation 1.4.10 to make clearer that response should be based on an initial 'triage', and that the response of 1 hour is for phone response only. Face to face response is suggested within 4 hours if required following triage and assessment. The resource impact report that considers the costs and benefits of these recommendations, identified providing intensive support in a crisis (after the initial telephone triage assessment) as an area that would be likely to incur additional costs. However, evidence found that people from a wide range of groups were at more risk of being placed out of area, especially people that had more complex support needs, and providing intensive support during a crisis will reduce the likelihood of people being placed out of their local area.
Peer reviewer (PB)	Short	22	16		"[display} behaviour that challenges" - consistency	Thank you for your comment. we use the term 'learning disabilities and behaviour that challenges' to be consistent with the clinical guideline that accompanies this service guideline (NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11
Peer reviewer (PB)	Short	23	15		Consider recommending review similar to CETRs? Introducing scrutiny by independent experts to all OOA placement requests?	Thank you for your comment. The review recommended in this recommendation would be similar to a CETR but is not covered by this process. Reference to an independent expert by experience has been added, in line with the CETR process.
Peer reviewer (PB)	Short	23	7		Not all children and young people in this cohort will be eligible for an EHCP – advise "...where eligible, or suitable alternative"	Thank you for your comment. The recommendation has been revised to make reference to 'or other relevant plan'.

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Peer reviewer (PB)	Short	24	9		Does this include residential schools? If so this could be more clearly stated? Restrictive is interesting in this context – though not necessarily wrong. Reducing restrictive practices at residential school should be highlighted.	Thank you for your comment. This recommendation has been amended so that it does not refer to residential settings as 'restrictive', but focuses on moving back home, if appropriate, or towards independence.
Peer reviewer (PB)	Short	25	24		CTR/ CETR Should this be an example or a recommended model? It could be an example for residential schools and mandated here?	Thank you for your comment. It was the view of the Guideline Committee that processes other than CTRs or CETRs would be appropriate, provided they fulfil the function of reviewing and discuss all available options.
Peer reviewer (PB)	Short	27	2		Not sure about "Think about..." prefer "ensure consistency in planning processes including CETR and EHCP processes"	Thank you for your comment. Reference to the Education, Health and Care Plan (EHCP) process has been added to the recommendation.
Peer reviewer (PB)	Short	28	4		Which commissioners? Should this read "Local areas..."?	Thank you for your comment. The recommendation has been changed as you suggest.
Peer reviewer (PB)	Short	29	2		Expert by experience - This definition excludes people and their families who have managed similar diagnosis/ needs without displaying challenging behaviour – this group often has useful insight into alternatives to admission/ specialist support options and in my view should not be discounted.	Thank you for your comment. The definition of "expert by experience" has been amended so that it does not refer specifically to behaviour that challenges.
Peer reviewer (PB)	Short	4	3-4		Is this figure adults or all-age?	Thank you for your comment. This figure refers to all ages. This has been clarified in the background to the guideline.
Peer reviewer (PB)	Short	4	4		"behave in a way that challenges" – consider "display behaviour that challenges"? - consistency	Thank you for your comment. We have amended this text as you advise in the first sentence of the background section.. However throughout the rest of the guideline we use the term 'learning disabilities and behaviour that challenges' to be consistent with the clinical guideline that accompanies this service guideline (NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11
Peer reviewer (PB)	Short	8	24		Relates to comment above. All commissioners have a responsibility here? – would the Lead commissioner be accountable for ensuring people who display challenging behaviour are taken account of in the commissioning all services? For example leisure/ school nursing/ dentistry (etc. etc.) – can you clarify "acting through" and name different responsibilities i.e commissioning, ensuring consideration, liaison with other commissioners to ensure etc.? Or is this comment in relation to specialist services relating to difficult behaviour – issue of scope	Thank you for your comment. We have amended this recommendation to read '… commissioning of health, social care and education services **specifically for** children, young people and adults with a learning disability, including those who display, or are at risk of developing behaviour that challenges' in order to clarify that this person would not be expected to commission universal services that could be accessed by this population.
Peer reviewer (PB)	Short	8	5		Which functions/ services would this include? Specialist – Intensive Support/ Assertive Outreach, PBS – Assessment and Treatment? Should this read "commissioning [specialist] health, social care and education services"? Do they also have a role in ensuring other non-specialist services are accessible to people who display behaviour that challenges – leisure services, supported employment etc.? Should this be also stated here? Some functions would already have other commissioners for eg Short Breaks – what is the role of the "Lead Commissioner" in these? Liaison role – providing advice and specialist knowledge?	Thank you for your comment. We have amended this recommendation to read '… commissioning of health, social care and education services **specifically for** children, young people and adults with a learning disability, including those who display, or are at risk of developing behaviour that challenges' in order to clarify that this person would not be expected to commission universal services that could be accessed by this population.
Peer reviewer (PB)	Short	9	17		As above the lead commissioner should currently reads "develop" could this/ should this read "ensure there are...", "oversee", "facilitate" – it is likely there will be more than one commissioner involved – I cannot envisage a local arrangement where a single commissioner would be responsible for commissioner such a diverse range of services across all ages and all agencies - as mentioned throughout this document – CLDTs, Therapy Services, Educational Psychologists, CAMHS, Housing, Intensive Support Teams, Short Break Services etc.	Thank you for your comment. We have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.

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Peer reviewer (SN)	Short	10	14		Could we add something about numbers of complaints and responses to these	Thank you for your comment. This recommendation refers to sources of data that should be used to ensure that services meet service-level and individual outcomes. Complaints data was not thought to be a source of evidence for demonstrating these outcomes.
Peer reviewer (SN)	Short	12	23		Or disabled children's team (very unlikely to have children's social workers in a CLDT)	Thank you for your comment. We have added reference to disabled children's teams to this recommendation.
Peer reviewer (SN)	Short	13	2		A CLDT more usually reflects adult provision, so may be helpful to include a cyp equivalent	Thank you for your comment. Reference to children's services has been added to this recommendation.
Peer reviewer (SN)	Short	14	28		Could there be some reference to the use of Integrated Personal Commissioning here.	Thank you for your comment. Our understanding is that Integrated Personal Commissioning is not currently available across England.
Peer reviewer (SN)	Short	15	19		Links to the local parent carer forum	Thank you for your comment. Reference to parent carer forums has been added to the recommendation.
Peer reviewer (SN)	Short	16	11		I really dislike the use of the term respite – as the definition of this is the laying down of a burden. Aiming High for Disabled Children (2008-11) replaced this terminology with "Short Breaks" which is widely used in children's services. Please consider using this terminology	Thank you for your comment. We have amended the term 'respite' to 'short breaks' throughout, and included a definition of short breaks in the 'Terms used' section.
Peer reviewer (SN)	Short	16	7		Again – adult focused	Thank you for your comment. Reference to the community learning disability team has been removed from this recommendation so that it simply reads 'the named worker should'. This applies equally across children's and adults' services.
Peer reviewer (SN)	Short	17	16		Clarify available out of usual office hours	Thank you for your comment. Out-of-hours services are described in recommendation 1.4.10.
Peer reviewer (SN)	Short	19	24		Please include "which for children and young people is clearly set out in the Local Offer"	Thank you for your comment. The recommendation has been amended as you suggest.
Peer reviewer (SN)	Short	20	27		Could you include something about supporting families caring for a child or young person to access appropriate housing. I think there definitely needs to be some reference in here to the housing challenges faced by families caring for children with behaviours that challenge	Thank you for your comment. We did not find any evidence relating to housing for families caring for children and young people, and the Guideline Committee did not raise this as a priority that needed an expert witness or to make a research recommendation. We do however refer to the Care Act in many recommendations, and this has duties on Local authorities to recognise housing as a health related service where this promotes the health and wellbeing of that person.
Peer reviewer (SN)	Short	22	20		Can you clarify what you mean by this? Disabled children and young people are considered to be "In Need" under the Children Act 1989, and there are clear requirements to assess their needs and if necessary provide services to support children and families. However, I don't think the Children Act states anywhere that local authorities had a duty to provide specialist learning disability services. You may need to reword this to reflect that local authorities are required to provide a range of services for Disabled Children and have a duty to support children and young people to enable them to remain living with their families through provision of a range of services and support – including short breaks.	Thank you for your comment. The intention of this recommendation was that local authorities have a duty to enable children and young people to stay with their families, through the provision of a range of services – as you have stated. We have reworded the recommendation to make this clearer.
Peer reviewer (SN)	Short	23	10		I think this needs some rewording as well – you may want to include a reference to the Lenehan / Geraghty review "Good intentions – good enough?"	Thank you for your comment. We have added reference to the Lenehan review to the context section.

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Peer reviewer (SN)	Short	23	15		Could suggest using the CETR template or similar	Thank you for your comment. The review recommended in this recommendation would be similar to a CETR, but is not covered by this process. Reference to an independent expert by experience has been added, in line with the CETR process.
Peer reviewer (SN)	Short	23	6		After Education, health and care plan please add "or other relevant plan" as children may be supported through SEN support and not have an EHC plan.	Thank you for your comment. The recommendation has been amended as you suggest.
Peer reviewer (SN)	Short	24	12		Please include " This could be done as part of a Looked After Child review, or EHC review.	Thank you for your comment. The recommendation has been amended as suggested.
Peer reviewer (SN)	Short	24	22		Please see previous comment on the use of respite care	Thank you for your comment. The term 'respite care' has been replaced with 'short breaks' throughout.
Peer reviewer (SN)	Short	24	26		May want to refer to the legislative requirement to provide a range of short break services for children and young people, and local authorities duties to provide a Short Break Statement outlining their services and eligibility criteria (Children and Young Persons Act 2008) This should be published on the Local Offer website (Children and Families Act 2014)	Thank you for your comment. We have amended the wording of recommendation 1.7.1 to make clearer that this is a statutory duty.
Peer reviewer (SN)	Short	24	8		I don't think this wording is quite right. Why would there be an assumption that a residential school / home is a restrictive setting? Would want to ensure there is a robust review of the placement, and if children are placed at distance this is always considered and placements closer to home are sought.	Thank you for your comment. This recommendation has been amended so that it does not refer to residential settings as 'restrictive', but focuses on moving back home, if appropriate, or towards independence.
Peer reviewer (SN)	Short	25	16		Could we change wording to "…show that their assessment, care and treatment cannot be safely undertaken in the community"	Thank you for your comment. We have retained the wording 'needs' so as not to imply that this only relates to care and treatment units.
Peer reviewer (SN)	Short	25	18		I think this needs to be much stronger to reflect the before any inpatient admission is agreed, a Care (Education) and Treatment Review must be undertaken in line with policy	Thank you for your comment. The wording of the recommendation has been strengthened to make clear that guidance for how to undertake this process is set out in the Care, (Education) and Treatment Review procedures.
Peer reviewer (SN)	Short	25	24		The link to the policy is helpful but I don't think it should an example of this is ….. I think it should be "The policy and guidance about Care (Education) and Treatment Reviews can be found here…"	Thank you for your comment. The recommendation has been amended as you suggest.
Peer reviewer (SN)	Short	26	6		For children it is usually Specialised Commissioning in NHS England that would scope and secure the placement	Thank you for your comment. This recommendation has been amended to read 'commissioners' in light of your comment.
Peer reviewer (SN)	Short	28	26		I am a little confused about this definition of children. The UN Convention on the Rights of the Child defines a child as everyone under 18 unless under the law applicable to the child, majority is attained earlier. The law assumes that by the age of 16 young people are able to make decisions about their own care depending upon capacity. I assume NICE use this for other guidelines but would question how this has been arrived at.	Thank you for your comment. The definitions of children and young people in the guideline have been aligned with those in (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), of which this guideline is a counterpart. We have amended the definitions in the 'terms used' so that it is clearer that the terms 'children and young people' cover the age group up to 18.
Peer reviewer (SN)	Short	30	6		Please see comment above re definition of children	Thank you for your comment. The definitions of children and young people in the guideline have been aligned with those in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have amended the definitions in the 'terms used' so that it is clearer that the terms 'children and young people' cover the age group up to 18.
Peer reviewer (SN)	Short	31	14		I think this is more nuanced for children and young people. There are clear policy guidelines about placing children away from their families, and if decisions are made to do so, then you would expect this to be monitored through the Looked After Children Regulations, or Visiting Children in	Thank you for your comment. The view of the Guideline Committee was that residential settings should also only be offered if all other options have been considered, and that there should be ongoing review for moving children and young people back home from residential placements.

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					Residential Schools. However, where decisions have been made to place children in residential schools or care homes, you would expect there to be long term planning for them, and it may be that remaining in that placement is their long term plan. I think you need to clarify the different between inpatient settings – where clearly the aim is to plan for children to move to less restrictive placements or back home as soon as possible, and school or care settings, where there may be different considerations.	
Peer reviewer (SN)	Short	31	17		Generally – this seems light in relation to the role of, or responsibilities of education for children and young people, as education often play as vital a role (if not more) than social care. Is there any scope for highlighting this a little more?	Thank you for your comment. Reference to professionals working with children and young people was added to recommendations 1.2.10, 1.2.15, 1.2.17 and 1.4.5. References to Education, Health and Care plans for children and young people were also added to 1.2.12 and 1.8.11. NICE's remit is about making recommendations for health and social care and they are the primary audiences for this guideline. We have included education in recommendations where this is particularly relevant, and included education providers and practitioners as secondary audiences for the guideline.
Peer reviewer (SN)	Short	5	17		Could we add in here "Supplementary guidance about developing support and service for children and young people with learning disability, autism or both – a supplement to the Service Model – was published in September 2017	Thank you for your comment. The context now makes reference to the Transforming Care guidance on Developing support and services for children and young people with a learning disability, autism or both. We have also made clearer that the current guideline covers people with a learning disability and autism.
Peer reviewer (SN)	Short	5	General		The information about Transforming Care is useful, but I wonder whether it would be helpful somewhere to include the fact that Transforming Care covers those with a learning disability, autism or both and behaviours that challenge and / or a mental health condition. I appreciate this guidance is in relation to learning disability, but would be good to reference that TC applies to those with autism or autism and a learning disability.	Thank you for your comment. The context now makes reference to the Transforming Care guidance on Developing support and services for children and young people with a learning disability, autism or both. We have also made clearer that the current guideline covers people with a learning disability and autism.
Peer reviewer (SN)	Short	6	6		Include: Chronically Sick and Disabled Persons Act 1970 Children and Young Peoples Act 2008	Thank you for your comment. We have included reference to and links to these documents in the list of relevant legal duties and guidance.
Peer reviewer (SN)	Short	7	20		Could this read "move away from their home or community for their care education or treatment"	Thank you for your comment. We have amended this text as you suggest.
Peer reviewer (SN)	Short	8	16		Could we add "Particularly those who may form part of a Transforming Care Partnership footprint"	Thank you for your comment. This has been added as you suggest.
Peer reviewer (SN)	Short	8	9		Do we need to add in a comment here where if the lead commissioner for children and young people is different than the adult commissioner, they need to ensure they work closely together	Thank you for your comment. The Guideline Committee discussed this, and were keen that there should be a single lead commissioner with responsibility for children's and adults' services. However, the committee has amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Peer reviewer (SN)	Short	9	9		Please add after at risk of admission "dynamic risk stratification processes, disabled children's register"	Thank you for your comment. Reference to dynamic risk data and disabled children's registers have been added to this recommendation.
Real Life Options	short	10	8-11	1.1.8	We are concerned that this could lead to commissioner stating numerous specific, validated outcome tools. Whilst appreciating this is a good thing to do, the reality is that many providers work across a number of commissioning authorities and it is not practical for a provider to use a number of different outcome tools and to ensure staff are trained and competent to a sufficient level on these tools. Therefore we would look for guidelines that recommend the use of an outcomes framework or process, but not restricted to pre-validated tools.	Thank you for your comment. This recommendation includes a range of suggestions for how outcomes could be measured rather than an exhaustive or prescriptive list. It has been updated following stakeholder consultation feedback and now includes reference to quality of life ratings, quality checks by user organisations and quality review visits from community learning disability teams.
Real Life Options	short	11		1.2	1.2 We are very supportive of the comprehensive nature of the guidelines on person-centred care. We feel this backs up the ethos of Real Life Options and	Thank you for your comment and your support for these recommendations.

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					will enable us to insist on this approach when working in partnership with other agencies.	
Real Life Options	short	12	22-24	1.2.9	We are fully supportive of this statement. Whilst many of the local authorities fulfil this guideline already this is not always the case. This can cause issues for us as a provider as this means an individual's history is lost and there fails to be coherent communication and coordination between agencies. Having a single practitioner is of critical importance to families who will then have a single first point of contact.	Thank you for your comment and your support for the recommendation.
Real Life Options	short	13	12-28	1.2.12	We are pleased that providers as seen as partners with the person who displays behaviour that challenges, their family and community learning disability teams to develop and deliver the care and support plan. We know that it can be very positive to be able to bring our experience, and often knowledge of a person, to the table and that by working co-productively this can result in better outcomes.	Thank you for your comment and support for this recommendation.
Real Life Options	short	13-14	29-8	1.2.15	We believe this is critical. We have had situations where, as a provider, we have found ourselves having to take the lead on review, in the absence of the council nominee. This causes a potential conflict of interest and means that coordination across the agencies is poorer.	Thank you for your comment and your support for the recommendation.
Real Life Options	short	15	14 - 23	1.3.3	Information should include what providers there are and what they offer.	Thank you for your comment. This recommendation is about types of support and not individual providers. However, in recommendation 1.3.3 we suggest that information about support and services could be made in the form of a 'welcome pack', this could include what providers there are and what they offer. The information provided should relate to the recommendations in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), that relate to the support and interventions for family members or carers. We have provided a hyperlink to this section for people who wish to know more.
Real Life Options	short	16	7-19	1.3.5	Information about providers should be included here, not only for respite care services.	Thank you for your comment. The recommendation is about providing information about rights and how to access services. It does not cover specific providers. The Guideline Committee thinks that the wording is sufficient.
Real Life Options	short	17	18-30	1.4.3	List should include support workers, care workers, outreach services etc.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. .
Real Life Options	short	18	6-14	1.4.4	Fully supportive of this and believe this standard will help us to maintain values based approach.	Thank you for your comment and your support for the recommendation.
Real Life Options	short	22	7	1.5.8	This should read either 'day services' or 'day opportunities'	Thank you for your comment. We have revised this recommendation (now recommendation 1.2.23), as you suggested.
Real Life Options	short	26	3	1.8.6	Reference should also be made to the advocacy duty under the Care Act 2014	Thank you for your comment. We have revised recommendation 1.8.3 to read that people should be given information about their rights, and access to independent advocacy and other possible options for treatment, and care and support.
Real Life Options	short	8	14-18	1.1.3	Whilst we understand the potential benefits of pooling budget we are concerned that there could be unintended consequences of regional services that are funded in this way being a distance away from people's homes, families and communities.	Thank you for your comment. The Guideline Committee agreed on the importance of ensuring people are enabled to stay in their home area, near their family and community. This is referenced in the 'Aims and Principles' section and more specifically in recommendations: 1.2.23, 1.4.7, 1.4.10, 1.4.12-1.4.14, 1.5.2, 1.5.7, 1.6.4, 1.6.10, 1.8.5-1.8.7.
Real Life Options	short	8	19-21	1.1.4	We are fully supportive of this recommendation. We would want to stress that providers have the skills and experience to work creatively to meet the individual support needs of people with behaviour that challenges. It is important that providers are part of a multi-agency process in order to ensure	Thank you for your comment and support for this recommendation. The importance of having appropriately skilled professionals is addressed in recommendations within section 1.9 and in 1.2.15. The importance of provider involvement in service planning is also referenced in 1.1.10, 1.1.13, 1.2.10. 1.2.14 and 1.2.19.

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					there is capacity in the community that can respond to specific needs when they arise.	
Real Life Options	short	8	2 - 9	1.1.1	We are fully supportive of the designation of a single lead commissioner, with specialist knowledge. Our experience of working with a single lead commissioner is of much better outcomes for people we support.	Thank you for your comment and your support for the recommendation.
Real Life Options	short	8	27-29	1.1.5	We must emphasise the importance of local authorities and commissioning groups having clear data about the amount of current and future local service needs. It is important that this is shared with social care providers if it is hoped that there will be diversity, choice and capacity in future provision.	Thank you for your comment and support for this recommendation.
Real Life Options	short	9	20-21	1.1.6	It is vital that local authorities take a strategic approach, using information about current and predicted need to work alongside families and providers to ensure there is capacity, but also innovation and creativity in the system.	Thank you for your comment and support for this recommendation.
Real Life Options	short	9	27-31	1.1.7	We are not clear what is meant by 'joint responsibility with providers' in this statement? This section presumably refers to the risks associated with developing a new form of support.	Thank you for your comment. We have revised this recommendation to say: 'The lead commissioner should take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. They should aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person'.
Real Life Options	Short	general		general	We are very supportive of this guideline. As a provider we believe that, on the whole, this encourage better communication between people with behaviour that challenges, their families and agencies and will therefore support us in providing high quality person centred support.	Thank you for your comment and support for this guideline.
Real Life Options	short	general		general	We are pleased that, on the whole, providers of support are seen as partners in enabling person centred support for people with behaviour that challenges.	Thank you for your comment and support for this guideline.
Real Life Options	short	general		general	We are pleased that the guidelines reinforce key reports including the Mansell Report and Transforming Care. We believe that this will support us to drive forward these principles when we are negotiating with commissioners.	Thank you for your comment and support for this guideline.
Respond	Short	11	22	1.2.3	Include "and their life history" at the end of the sentence	Thank you for your comment. We have now amended this recommendation to include reference to 'life history', where the relevant bullet point read as follows: 'takes into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems and their life history'.
Respond	Short	12	11	1.2.7	Include "and psychological therapists" after the word "communication"	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Respond	Short	12	24	1.2.9	Include "for a continuous amount of time (e.g. minimum 1 year)" after the word "support"	Thank you for your comment. We have revised the recommendation to say that care and support needs to be coordinated over the long term.
Respond	Short	13	3	1.2.11	Change "their family members and carers" to "significant people e.g. non-abusive family, key friends and carers"	Thank you for your comment. We have revised this recommendation to read 'family members, carers and advocates'.
Respond	Short	14	1	1.2.15	After "placed out-of-area" include or if there has been a bereavement."	Thank you for your comment. After careful consideration, we think that providing one illustrative example of a significant change is appropriate.
Respond	Short	15	23	1.3.3	Insert new bullet point after line 23 and include "counselling support"	Thank you for your comment. The recommendation includes examples of different ways of providing support, not specific interventions. Individual interventions are not in scope for this service guideline.
Respond	Short	16	29	1.4.1	Insert new bullet point after line 29 and include "could be purchased specialist services such as Circles of Support and Accountability (CoSAs), risk analysis and/or psychotherapy	Thank you for your comment. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions as this is in scope for the clinical guideline that accompanies this service guideline: Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.
Respond	Short	17	30	1.4.3	Insert new bullet point after line 30 and include "psychotherapists" then insert new bullet point and include "creative therapists"	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.

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Respond	Short	18	14	1.4.4	Include another bullet point that says "reflective"	Thank you for your comment. We have revised the wording to include 'reflective'. This describes being able to reflect and respond to past performance.
Respond	Short	18	17	1.4.5	Include "or specialist voluntary sector organisations" after "forensic teams,"	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals are needed.
Respond	Short	19	16	1.4.9	Include "and/or a psychological approach" after "mental health problems"	Thank you for your comment. The Guideline Committee agreed that the level of detail and focus in this recommendation was sufficient.
Respond	Short	19	3	1.4.7	Include "and/or psychological" after "behavioural"	Thank you for your comment. The recommendation is specifically about specialist behaviour support.
Respond	Short	20	12	1.4.13	Include "For example through setting up a Circle of Support and Accountability (CoSA)." After "their community."	Thank you for your comment. The Guideline Committee's view is that the wording in the recommendation is sufficient.
Respond	Short	20	16	1.4.15	Include "specialist voluntary sector organisations" after "mental health, learning disability"	Thank you for your comment. We have revised the wording of the recommendation as you have suggested.
Respond	Short	22	16	1.6.1	Include "or specialist voluntary sector organisations." after "behaviour that challenges"	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals are needed
Respond	Short	7	17	Aims and principles	Include another bullet point after this of "recognise the affect that a person's history may have on their behaviour"	Thank you for your comment. We have revised the recommendation 1.2.5 to include taking account a person's life history when supporting people to live where and how they want. Specific factors associated with behaviour that challenges is in scope of the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Royal College of General Practitioners	Short	11	16-27	1.2.3	As above, only in this list the overarching aim is listed second, not third.	Thank you for your comment. We have retained the order of the examples of how and to what purpose families and carers are involved in the care and support of children young people and adults, with the first being that involvement should still start with being person centred, reflecting the individual needs and choices and maximising their control.
Royal College of General Practitioners	Short	12		1.2.6	My concern though is with frailty and decline towards end of life and risk avoidance which can and has led to perhaps the wrong decisions. I Specifically I am thinking about PEG insertion in those who are deemed by the SALT team as a choking risk. Homes are then almost pressed into this being done to their clients and they then lose the long individual attention during meals and also sadly, in my opinion, a very long drawn out natural death. Few with capacity agree to this (in my experience). When they finally reach the last few days they will trigger 'sepsis 'alerts if ringing 111 and will end up as a 999 admission. The new death reviews of all with LD may show up areas of concern but the potential flip is a peaceful planned death may be harder to happen knowing all actions will be reviewed perhaps by those with no knowledge of the individual or their families I realise the above may be seen as being out of place with the whole document and certainly agree this service using group gets a raw deal in many ways and needs improving.	Thank you for your comment and support for this guideline. NICE is currently developing two guidelines that are relevant to your comment: Care and support of older people with learning disabilities and Decision making and mental capacity. Both are expected to publish in 2018. Where there are overlapping guidelines, the NICE website signposts readers to relevant recommendations via their interactive, web-based pathways.
Royal College of	Short	7	11-17	Aims and principles	There is, of course, nothing to disagree with in these principles. However, the order maybe wrong. Number 3, in line 13 should be the overall aim of care (again for all patients, not just these); the others are all the means by which	Thank you for your comment. We have changed the Aims and Principles to the following order based on your suggestion and further Guideline Committee consideration: • Help people to have a good quality of life • Help people achieve physical and mental health and emotional wellbeing.

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General Practitioners					this one is achieved. One suggestion would be that the order is changed to reflect this.	
Royal College of General Practitioners	Short	General		general	This is an interesting example of a NICE document where, as an otherwise ignorant reader is concerned, there is little research to guide specific actions. (I should own up that I haven't looked at the evidence base in the full guideline). The result is that the recommendations end up articulating principles of good medical practice, and add nothing to what ordinarily competent care workers should be doing already – and doing for all patients, not just those with learning disabilities. There are some recommendations such as those concerning provision of specialist services and respite care, could influence commissioners; but I cannot see it doing anything other to clinicians than make them feel thoroughly patronised.	Thank you for your comment. The focus of this guideline is on service design and delivery, rather than clinical practice. There is a separate clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). The Guideline Committee agree that there is much that is already known about good practice in this area, but it was strongly felt, that at least in some areas this was not happening in practice. The recommendations in the guideline, although not mandatory, encourage health and social care and other practitioners, and practitioners in related services, to follow our recommendations to help them deliver the highest quality care. The lack of research evidence in some areas is supplemented by evidence from expert witnesses and the experience and practice knowledge of the Guideline Committee. The deliberations and interpretation of the research evidence and what this means in practice for making recommendations is described in the 'Evidence to Recommendations' section in the full version of the guideline.
Royal College of General Practitioners	Short	General	General	General	As far as clinicians are concerned, most could come straight out of a textbook on good medical care for all.	Thank you for your comment. The Guideline Committee agree that there is much that is already known about good practice in this area, but it was strongly felt, that at least in some areas this was not happening in practice. This service guidance also aims to support local areas to rebalance services towards enabling children, young people and adults to live in their communities.
Royal College of General Practitioners	Short	General	general	general	As a GP having looked after 4 'care homes' for people with LD many for 25 plus years as well as individuals cared for at home or in community supported housings Telehealth. My understanding is that this has been shown to be of no use so why promote it in this group?	Thank you for your comment. As an area of interest to the Guideline Committee, we undertook an additional review of evidence for assistive technology to support independent living. We did not find robust evidence of its effectiveness, and so a research recommendation was made.
Royal College of Nursing	Short	10	12	1.2.7	Section 1.2.7: Those accessing mainstream services may not get access to specialists. Is there further information or is there going to be a link provided here?	Thank you for your comment. We make reference to people using services, having access to specialists via community learning disability teams, in recommendation 1.4.3
Royal College of Nursing	Short	10	12	1.2.8	1.2.8: Local authorities need to make aware how people can access this service.	Thank you for your comment. We agree and have covered this in recommendations (1.8.3 and 1.8.4) about providing information.
Royal College of Nursing	Short	11	11	1.2.2	Section 1.2.2: It very positive to see people with LD and their family and carers' experiences at the beginning of the guidelines - highlighting the role they play.	Thank you for your comment and support for these recommendations.
Royal College of Nursing	Short	14	11	1.2.3	Section 1.2.3: We would like to see overcoming barriers and taking positive risk (when appropriate).	Thank you for your comment. Recommendation 1.2.14 makes reference to taking a positive approach to managing risk.
Royal College of Nursing	Short	15	1	1.3	Section 1.3: Training in behaviour analysis and Positive Behaviour Support (PBS) is required – this needs to be rolled out across all health & social care services.	Thank you for your comment. In the 'putting this guideline into practice' section we emphasise the need for local authorities and health services to provide comprehensive support for families including the need for 'ongoing training and support for their caring role from specialist services, including positive behaviour support services'. We say in recommendation 1.3.5 that training for families and carers needs to be in line with recommendations 1.7.1 and 1.7.2 in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). Recommendation 1.9.2 says that staff providing direct support to children, young people and adults with a learning disability and behaviour that challenges need to have the 'direct contact' level competencies of the 'Positive behaviour support competence framework'.

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Royal College of Nursing	Short	15	28	1.3.4	Section 1.3.4: this is an excellent proposal.	Thank you for your comment and your support for the recommendation.
Royal College of Nursing	Short	16	1	1.3.5	Section 1.3.5: This needs to be shared with providers.	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. This is on the basis that the guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation.
Royal College of Nursing	Short	8	23	1.1.5	Section 1.1.5: This information has not been shared with other providers - i.e. Mental Health Services are not linked to this pathway. Clear guidance for local authorities and clinical commissioning groups is required in this pathway.	Thank you for your comment. The Guideline Committee considered current practice and good practice in developing the recommendations and agreed this recommendation was aspirational but achievable.
Royal College of Nursing	General	General		General	The Royal College of Nursing welcomes proposals to develop guidelines for Learning Disability and behaviour that challenges: service design and delivery. The RCN invited members who care for people with learning disability and who work in criminal justice nursing to review the draft and comment on behalf of the RCN. The comments below include the views of our reviewers.	Thank you for your comment and support for the guideline.
Royal College of Nursing	Short	General		general	We welcome many of the proposals in these guidelines. It is good to see that contact with criminal justice is highlighted. The guidelines need to ensure they capture good liaison and diversion and early intervention away from Criminal Justice System (CJS) where appropriate. The guidelines also need to ensure STOMP (Stopping over medication with people who have a learning disability as a default response. Recently published RCN guidance (2017) The Needs of People with Learning Disabilities is a useful resource to mention in supporting the implementation of these guidelines.	Thank you for your comment and support for the guideline. We agree it is helpful to highlight the importance of regularly reviewing medication. This is covered in recommendation 1.2.22. We reference the recommendations set out in the NICE guidelines - (Managing medicines for adults receiving social care in the community. NICE guideline NG67) and The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Royal College of Nursing	General	General		General	Whilst welcoming these guidelines we also consider that the government needs to give priority to how the guidelines would be implemented and in particular, by providing the much needed resources for this area. The current position is creating a situation for people with learning disability and challenging behaviour that is completely unacceptable because of NHS and local authority cuts. We, therefore, consider that having guidelines in a vacuum is not useful. There are also people diagnosed with a learning difficulty rather than a disability who also have challenging behaviours and have complex needs as raised in this guideline. Often there are few services available (often sometimes none) and is an unmet need for review and guidance.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and was aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Royal College of Nursing	General	General		General	The Learning Disability workforce is severely compromised to ensure effective safe delivery of quality care and support. This is highlighted in the recently published RCN Safe and Effective Staffing: the real picture Report (2017) which captures views of LD nurses within it. Learning disability workforce issues not only affect frontline staff but commissioning expertise is also lacking as most commissioners have little or no learning disability needs experience or appear not to be knowledgeable on where to look for relevant information to support people with these needs.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The Guideline Committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.

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Royal College of Nursing	Questions	Questions	Questions		*Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.* The areas listed below will have a large impact on practice and be challenging to implement. This is because they imply the setup of new services, changes in established working patterns and require funding and significant workforce change to introduce. Section 1.2.9 onwards: Where there are geographical variances in service provision. For example in South East London, learning disability services are not integrated; there is a social service, a health service and a mental health service – where would the responsibility lie for each of the recommendations in this section and how would budgets marry up? Section 1.4.9: What is local and how would this be feasible given costs/resource implications for such a small population? Most Community Team for Learning Disabilities (CTLDs) work 9-5 Monday to Friday. Are the guidelines proposing to set up 24/7 teams? Section 1.4.12: Not every locality has a Forensic Community Learning Disability Team. Are the guidelines suggesting that each area should have one, or each region or is it optional? Section 1.9.5: All support staff should have time on their roster for support and supervision – it should not be a luxury but normal part of practice built into systems to avoid burnout and to value staff doing a physically and emotionally labour intensive job. Other: The guidelines should note that offenders with a learning disability may have restrictions applied to them which means that their choices and wishes cannot be carried out (for example because that would threaten public safety; court order; probation; Mental Health Act etc.) but that least restrictive options are chosen in each circumstance.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable. With regard to recommendation 1.2.10, we have now made clearer that there should be multi-agency responsibility for assigning a named worker. Recommendation 1.4.10 has now been reworded to make clearer that initial response could be by phone, and that the service could be provided in partnership with other service providers. With regard to recommendation 1.4.12, this has been amended to make clearer that forensic services can be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning disability team. With regard to recommendation 1.9.5 we agree that supervision should be a part of people's roles. With regard to using least restrictive interventions for people with learning disabilities who show offending behaviour, the overarching principles for the guideline make reference to maximising choice and control.
Royal College of Nursing	Questions	Questions	Questions		2. *Would implementation of any of the draft recommendations have significant cost implications?* Yes. Some of the comments we made earlier about the areas that would make the most impact also apply and have significant cost implications. They are listed below:	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable. With regard to recommendations 1.2.10 onwards, these recommendations should be clearer now that we have clarified the role of the single lead commissioner as one who has strategic oversight for and plans and oversees joined-up commissioning arrangements. The Guideline Committee's view was that

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					Section 1.2.9 onwards: Where there are geographical variances in service provision. For example as previously commented, in South East London, Learning Disability Services are not integrated. There are Social Services, Health Service and Mental Health Services currently operating under separate systems and budgets – where would the responsibility lie for each of the recommendations in this section and how would budgets marry up? Section 1.4.9: As per previous comment, what is local and how would this be feasible given costs/resource implications for such a small population, and the fact that most community learning disability teams work 9-5 Monday to Fridays. Section 1.4.12 – not every locality has a Forensic Community Learning Disability Team. Are the guidelines suggesting that each area should have one, or each region or is it optional? Consideration needs to be given to the cost implications for this service. Section 1.9.5: All support staff should have time on their roster for support and supervision – it should not be a luxury but be normal part of practice built into systems to avoid burnout and to value staff who are doing a physically and emotionally labour intensive job.	this single lead commissioner would oversee commissioning across education, health and social care; and children, young people and adults' services, and will be able to work across systems and budgets. Recommendation 1.4.10 has now been reworded to make clearer that initial response could be by phone, and that the service could be provided in partnership with other service providers. The resource impact team considered the costs and potential savings of implementing intensive support in the community. Evidence found that people from a wide range of groups were at more risk of being placed out of area, especially people that had more complex support needs, and providing intensive support during a crisis will reduce the likelihood of people being placed out of their local area. With regard to recommendation 1.4.12, this has been amended to make clearer that forensic services can be provided as stand-alone teams, or as a specialism within an existing team, for example a community learning disability team. With regard to recommendation 1.9.5 we agree that supervision should be a part of people's roles.
Royal College of Nursing	Questi ons	Ques tions	Ques tions		*3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)* - Sharing of good practice models across the country to avoid duplication, consultancy between existing services and those wishing to set up similar services. - Ensure that people with lived experience are involved in consultations, service design and service delivery. - Ensure that all stakeholders are engaged and that prospective partner teams i.e. forensics, criminal justice, mental health teams, home treatment teams etc. are involved in developing shared care pathways or protocol etc.	Thank you for your comment. This guideline aims to support good practice. NICE also routinely produce baseline assessment and resource impact tools. To encourage the development of other practical support tools, we run an endorsement scheme aimed at encouraging our partners to develop these in alignment with NICE recommendations. Eligible tools are assessed and if successful, will be endorsed by NICE and featured on the NICE website alongside the relevant guideline.
Royal College of Ophthalmologists	short	12	7	1.2.6	A person's communication needs are intrinsically linked with their sensory function in particular vision. There are several publications highlighting the incidence of visual impairment in learning disability in adults and children. An article citing the unmet need in special schools was recently published and would support the need for specific targeted assessment of vision as part of a	Thank you for your comment. We agree that people's sensory function is an important part of their communication needs. This recommendation (now 1.2.21) has been revised to say that staff in all settings should aim to reduce the risk of behaviour that challenges developing by: • identifying health or sensory problems early

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					communication assessment. http://dx.doi.org/10.1136/bjophthalmol-2016-308534	• providing strategies and interventions to support communication. We have also made reference to psychological and environmental interventions within NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.
Royal College of Ophthalmologists	Short	13	22	1.2.14	Access to regular sight testing to identify sight loss as a cause for challenging behaviour is important in the management of new challenging behaviour. Staff should be equipped to signpost community optometrists for a biannual assessment or seek hospital referral. Staff should be aware of the visual needs of people with learning disability including the importance of supporting people in adapting to spectacle wear. Resources are available at seeability.org	Thank you for your comment. This recommendation (now 1.2.21) has been amended to make specific reference to early identification of health and sensory problems.
Royal College of Ophthalmologists	short	15	2	1.3.1	Restoring a patient's sight can eliminate challenging behaviour. Given that visual impairment is so common in people with learning disability and it is frequently unrecognised, support for families and carers should include regular visual assessment – be that at a high street optometrist, a special school service or hospital eye service. Restoring a patient's sight can eliminate challenging behaviour.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Royal College of Ophthalmologists	short	17	18	1.4.3	We are concerned that this list of professionals neglects vision entirely, despite there being a readymade resource in community optometrists. The current community optometry tariff however is inadequate for the additional time and adjustments required to assess someone with challenging behaviour. Steps should be taken to address this to allow all patients access to sight tests. Commissioning regular community assessments of vision such as the service in Bradford can proactively detect visual deterioration before it causes challenging behaviour. Support for patients and carers for those with untreatable visual loss can be offered by eye clinic liaison officers or visual impairment team (for those in education). Please contact Rachel.pilling@bthft.nhs.uk for more details of this service.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Royal College of Ophthalmologists	Short	22	11	1.6.1	Specialist assessment of a child with challenging behaviour should also include a visual assessment. Support to ensure visual aids such as spectacles are being used appropriately should be included.	Thank you for your comment. This recommendation relates to support for children and young people rather than assessment of health needs.
Royal College of Ophthalmologists	Short	22	2	1.5.8	Annual health checks include questions about vision but there are infrequent signposts for onward assessment given to patients/carers if concerns are raised. Many staff are unaware that visual assessments can take place in a patient who is unable to read or even speak. Specific direction on this has been offered via SeeAbility/VISION2020UK guidance https://www.seeability.org/Handlers/Download.ashx?IDMF=d8a91a3a-5f51-45ff-8073-e6ea5c7edf0e	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation.
Royal College of Ophthalmologists	Short	23	4	1.6.4	A change in challenging behaviour should trigger specific questioning around change in visual performance. A carer-led assessment tool "Visual Symptoms in Learning Disability" (VSLD) would be a suitable starting point (paper awaiting publication: email Rachel.pilling@bthft.nhs.uk for details)	Thank you for your comment. This recommendation focuses on multi-agency reviews, which includes both health practitioners and carers and would incorporate vision checks.

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Royal College of Ophthalmologists	Short	30	14	Putting this guideline into practice	Details of community adult vision services and special school visual assessment programme can be obtained from Rachel.pilling@bthft.nhs.uk	Thank you for your response. We will pass this information to our local practice collection team. More information on submitting examples of local practice can be found here.
Royal College of Paediatrics and Child Health	Short	11		1.2.3 to 1.2.4	Can an extra bullet point be added? -Make informed health decisions	Thank you for your comment. However, we did not find the research evidence to substantiate reference to making 'informed health decisions'. Please note that the guideline is based on the assumption that people have the right to be involved in discussions and make informed decisions about their care, which includes both health and social care.
Royal College of Paediatrics and Child Health	Short	12		1.2.5 to 1.2.9	We support the recommendations to work in partnership with all CYP, the inclusion of advocates and a dedicated practitioner 'named worker' to be assigned by a local authority	Thank you for your comment and your support for the guideline.
Royal College of Paediatrics and Child Health	Short	13		1.2.11	Could the following bullet point be added? -Support children and young people with communication needs (including those who are nonverbal)	Thank you for your comment. The Guideline Committee agree that support for communication needs is important. After careful consideration, we think that this is adequately covered in this recommendation (now 1.2.14) (and in recommendation 1.2.21).
Royal College of Paediatrics and Child Health	Short	15		1.3.3	Could the following bullet point be added? -Independent advocacy service	Thank you for your comment. We have revised the recommendation to include reference to advocacy.
Royal College of Paediatrics and Child Health	Short	6	5-9		Can the Human Rights Act 1989 be added please?	Thank you for your comment. We have assumed you mean the Human Rights Act 1998, which has been added to this list.
Royal College of Paediatrics and Child Health	Short	8		1.1.1	Please consider the creation of an advisory role for the lead commissioner and for this person to be someone with a LD	Thank you for your comment. Recommendation 1.1.14 recommends that commissioners should employ experts by experience in their commissioning teams to inform decision-making and quality assurance of services.
Royal College of Paediatrics and Child Health	General	General		General	Everything seems appropriate except that no real clue about who will have the training to offer a service.	Thank you for your comment. Training and qualifications of staff who deliver services are out of scope for this guideline, but included in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have referred to and provided a hyperlink to the clinical guideline where appropriate. We have included the positive behaviour competencies framework for both direct contact and consultancy level in the skills and competencies section which provides detailed information on what people should know and what they should do when using positive behaviour support approaches.
Royal College of Psychiatrists	full			definitions	Learning disability definition- is it worthwhile mentioning intellectual disability as an alternative word and learning difficulties are not the same thing, but have	Thank you for your comment and suggestion. We acknowledge that there are different terms used, over time and geographical area. To avoid confusion, we have used the term that is currently used in the literature and that has been used in the clinical guideline that accompanies this service guideline

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					overlap eg a learning disability is approximately a generalised (not specific) moderate to profound and multiple learning difficulty.	(Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Royal College of Psychiatrists	full		26/27	Putting this guidance into practice	Worthwhile adding 'ongoing training' or at least 'programme' or else they are going to be 'stuck' with the one-day limited training sessions	Thank you for your comment. We have revised this as you suggest to include ongoing training and support.
Royal College of Psychiatrists	full	10		1.1.12	1.1.12 Add consult with children and young people e.g. through investors in children groups	Thank you for your comment. The first sub-heading of section 1.2 has been edited to make clear that children and young people should be involved in planning of person-centred care and support.
Royal College of Psychiatrists	full	10		1.1.8	1.1.8 should it read 'and/or' their family members and carers rather than 'and'	Thank you for your comment. The Guideline Committee agreed to use the term 'families and carers' throughout. They agreed it is important to involve people in accordance with the person's wishes and preferences and this is reflected in the wording of recommendations 1.1.10, 1.2.4, 1.2.12 and 1.2.14. The guideline also cross-references the recommendations on involvement in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), recommendation 1.2.1.
Royal College of Psychiatrists	full	10		1.1.8	1.1.8 any child specific outcome tools that are relevant? CORC struggle to recommend any 'ethical' routine outcome measures	Thank you for your comment. This recommendation has been updated to include reference to quality of life ratings, quality checks by user organisations and quality review visits from community learning disability teams.
Royal College of Psychiatrists	full	11		1.2.2	1.2.2 or where decisions are made in a person's best interests through a lack of capacity	Thank you for your comment. We have revised the wording in recommendation 1.2.2 to read: 'Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005'. We have also revised recommendation 1.2.4 to read: ' Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the Mental Capacity Act 2005. This should be done unless there is a compelling reason not to (for example if there are safeguarding concerns)'.
Royal College of Psychiatrists	full	11		1.2.3	1.2.3Offers proactive and reactive plans to meet behavioural need	Thank you for your comment. We have revised recommendation 1.2.21 to say that in all settings, staff working with children, young people and adults with a learning disability and behaviour that challenges (and their families and carers) should aim to reduce the risk of behaviour that challenges developing by: • identifying health or sensory problems early • providing strategies and interventions to support communication. We also say to follow recommendations on psychological and environmental interventions in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). A hyperlink to the above guideline is provided for people to find more detailed information.
Royal College of Psychiatrists	full	12		1.2.7	1.2.7 Can the language not be strengthened to Speech and Language Therapists, Hearing Impaired Specialist or Intensive Interaction trained professional	Thank you for your comment. We have revised the recommendation to say 'speech and language therapy'. In recommendation 1.4.3, where the types of specialist support that should be made available through the community learning disability teams are listed, help in relation to communication is specifically included.
Royal College of Psychiatrists	full	13		1.2.11	1.2.11 there is something about adding skills teaching for the individual, and the systems supporting them in the care plan part.	Thank you for your comment. After careful consideration, we think that this is covered by reference to the persons' needs and preferences, and the lifespan approach.
Royal College of Psychiatrists	full	13		1.2.11	1.2.11 Should Learning Disability Child and Adolescent Mental Health Services be added (CLD teams are often adult only). This is an issue throughout the guidance. Perhaps have a qualifying statement that these include both child and adult services. The terminology used makes much of the document seem to be about adults with occasional references to children.	Thank you for your comment. The wording of recommendations has been revised throughout the guideline to make clear where recommendations apply to both children and adults. There are recommendations specifically about services for children and young people in Section 1.6.

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Royal College of Psychiatrists	full	13		1.2.11	1.2.11 Should transition plans be mentioned?	Thank you for your comment. Reference to supporting transitions through care planning has been added to recommendation 1.2.14.
Royal College of Psychiatrists	full	15		1.3.1	1.3.1 It mentions training on restrictive practice and how to reduce it but I think that proactive and non-aversive reactive management should be mentioned here too or it looks like you just need to know about one.	Thank you for your comment. Following stakeholder feedback, and further consideration by the Guideline Committee we have removed the term 'restrictive practice' from recommendation 1.3.1 and instead reworded the recommendation to cover the types of needs that parents and carers may need help with from specialist services.
Royal College of Psychiatrists	full	17		1.4.3	1.4.3 have access to physical health assessment and intervention e.g. GPs, Paediatricians, hospital specialists etc.	Thank you for your comment. Following stakeholder feedback, we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met, including physical health. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs.
Royal College of Psychiatrists	full	17		1.4.3	1.4.3 behaviour therapist – not a recognised qualification/ profession. It literally doesn't mean ANYTHING. There are qualifications e.g. in ABA, masters, qualifications etc. for professionals	Thank you for your comment. We have removed the term from recommendations when used as a profession title. We have kept the term behaviour support to be a generic term for behavioural interventions that are in line with the evidence based interventions in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Royal College of Psychiatrists	full	19		1.4.8	1.4.8 18 weeks appears to be too long for behaviours at this level of severity-risks of placement breakdown, injury to the person or others, risks of escalation to higher levels of response e.g. criminal justice, inpatient.	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or admission to hospital due to the lack of available specialist supports in the community.
Royal College of Psychiatrists	full	19		1.4.9	1.4.9 the crisis response needs support from physical health services e.g. dentistry, paediatricians, pain management etc.	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. It includes 'involve partnership with other commissioners, providers and family members' which could include health services.
Royal College of Psychiatrists	full	20		1.4.11	1.4.11 Adult forensic inpatient services might be more readily available at a local level however child and adolescent inpatient services for this group are national provisions and unlikely to be local.	Thank you for your comment. This recommendation is about the provision of community forensic services and not inpatient services. The recommendations related to making the right use of inpatient services are in section 1.8 of the guideline. The Guideline Committee strongly agree that admitting children, young people and adults to inpatient units should only happen if assessment and care planning show that their needs cannot be safely met in the community and all possibilities for doing so have been considered and exhausted.
Royal College of Psychiatrists	full	20		1.4.12	1.4.12 what about children/adolescents? - these services do not generally exist.	Thank you for your comment. We have revised the wording of the recommendation to include children and young people.
Royal College of Psychiatrists	full	22		1.6.3	1.6.3 Third bullet point – it would be strengthened by some working about skills teaching and independence.	Thank you for your comment. The recommendation has been edited accordingly.
Royal College of Psychiatrists	full	25		1.8.1	1.8.1 mention CTR/CETR processes/guidance	Thank you for your comment. These processes are referenced in recommendation 1.8.2.
Royal College of Psychiatrists	full	25		1.8.2	1.8.2 mention mental health act and emergency admissions has its own processes.	Thank you for your comment. The recommendation is about the people that need to be involved in the relevant discussion. The Guideline Committee felt that adding mention of the Mental Health Act was not needed here. There are references to the Mental Health Act elsewhere in the guideline under recommendations 1.2.8, 1.8.4 and 1.8.13., and in the legal duties and other guidance section of the guideline.

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Royal College of Psychiatrists	full	26		1.8.5	1.8.5 for adolescents, the inpatient estates are national, not local in their nature.	Thank you for your comment. The wording of the recommendations follow from other recommendations on building capacity in the community, which if implemented, would mean that admission to hospital will only be based on clinical need and not because of a lack of more appropriate services in the community. Where inpatient service are appropriate and necessary, and after all other options have bene considered, the Guideline Committee considered that people should be placed as close to home as possible
Royal College of Psychiatrists	full	27		1.9.1	1.9.1 Final bullet point about values, there isn't anything about respecting the individual's right to 'an ordinary life'.	Thank you for your comment. While we have not used the words "ordinary life" we have held to this principle through the recommendations.
Royal College of Psychiatrists	full	6		Legal duties	should MHA 2007 and CTR/CETR guidance 2017 be included in the relevant legislation list? Royal College of Psychiatrists	Thank you for your comment. We have included CETR guidance in recommendation1.8.2. We have included the MHA1983 in the list of relevant legislation because it is a primary piece of legislation. We haven't included the MHA 2007 in the list because it is an amending act, to make changes to primary 1983 legislation
Royal College of Psychiatrists	full	9		1.1.6	1.1.6 Is a single care pathway appropriate for lifespan? CB is a very different issue in early childhood. Or should be an overarching person centred care pathway with variation upon an individual's age and needs?	Thank you for your comment. We agree that there should be a care pathway that is person-centred, this is reflected in the Aims and Principles and recommendation 1.1.2 that say there should be a whole-life approach to planning for services
Royal College of Psychiatrists	full	general		general	Overall should we not be moving to Intellectual Disabilities in line with DSM-5 and ICD-11? Rather than Learning Disabilities.	Thank you for your comment and suggestion. We acknowledge that there are different terms used, over time and geographical area. To avoid confusion, we have used the term that is currently used in the literature and that has been used in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Royal College of Psychiatrists	full	general		general	We think that the PowerPoint is a helpful summary, and we would welcome this addition in guidance relating to child mental health.	Thank you for your comment and support for the guideline and summary.
Royal College of Psychiatrists	short	general	general	General	Few feel that the short guidance should address the issue of transition, particularly in view of the fact that the full draft guidance references a number of studies that highlight the difficulties in transition, as well as the fact that NHS England have now issued a CQUIN addressing Transitions out of Children and Young People's Mental Health Services.	Thank you for your comment. The transition from children to adult services is the subject of another guideline (Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43) and out of scope for this guideline. The Guideline Committee did consider that the role of the lead commissioner, who would have oversight of both children's and adult services and take a whole life approach to planning for services would ensure that people experienced minimal transition between services.
Royal College of Speech and Language Therapists	Short			1.6	We suggest highlighting the importance of including speech and language therapy at an early age, in order to promote activities which facilitate learning speech, language and communication with the family and education staff	Thank you for your comment. NICE guidelines aim not to duplicate guidance which is provided elsewhere. The provision of speech and language therapy is covered in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Royal College of Speech and Language Therapists	Short	10		1.1.8	While the RCSLT believes these are good tools for measuring process and quality assurance they are not outcome measures. We suggest you consider Therapy Outcome Measure which is being used as an outcome measure by many AHP's working with individuals with learning difficulties. We also suggest adding the importance of collecting local data on the needs of the individuals, including their ability to communicate and mental capacity for benchmarking and quality assurance	Thank you for your comment. This recommendation has been updated to include reference to quality of life ratings, quality checks by user organisations and quality review visits from community learning disability teams.
Royal College of Speech and	Short	12		1.2.6	We believe the particular expertise of speech and language therapists should be highlighted as a resource that can assist with this	Thank you for your comment. This has now been revised to reference the Accessible information standard recommendation 1.2.6 states that staff working with children, young people and adults with a learning disability and their families should find out their information and communication needs, record

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Language Therapists						them and share this information with everyone working with them in line with the Accessible Information Standard.
Royal College of Speech and Language Therapists	Short	12		1.2.7	The RCSLT suggest explicitly mentioning speech and language therapy in this section.	Thank you for your comment. Individual interventions are not in scope for this service guideline. However, we have revised recommendation 1.2.7 to say 'speech and language therapy'. In addition, in recommendation 1.4.3 where the types of specialist support that should be made available through the community learning disability teams are listed, help in relation to communication is mentioned.
Royal College of Speech and Language Therapists	Short	12	7	1.2.6	We suggest adding links to the Five Good Communication Standards and Accessible information standard here https://www.rcslt.org/news/docs/good_comm_standards https://www.england.nhs.uk/ourwork/accessibleinfo/	Thank you for your comment. We have revised this recommendation to include reference to the Accessible Information Standard. We will also pass this information to our resource endorsement team. More information on endorsement can be found here: (https://www.nice.org.uk/about/what-we-do/into-practice/endorsement).
Royal College of Speech and Language Therapists	Short	13		1.2.11	The RCSLT suggest mentioning the importance of regular reviews by specialists with expertise in learning difficulty	Thank you for your comment. Reference to review of care plans has been added to recommendation 1.2.16.
Royal College of Speech and Language Therapists	Short	13		1.2.11	The RCSLT recommends that the care plan should take into account the development and deterioration of communication needs and how this affects the individual's voice in care planning	Thank you for your comment. After careful consideration, we think that this is adequately covered, as the recommendation relates to holistic needs.
Royal College of Speech and Language Therapists	Short	15		1.3.1	The RCSLT is pleased to see that local authorities should refer individuals to speech and language therapy for crucial support with communication	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Royal College of Speech and Language Therapists	Short	15		1.3.2	Often our members refer to challenging behaviour as challenging communication. We see a crucial role for speech and language therapists here in training and supporting families and carers in understanding and responding to individuals.	Thank you for your comment. Individual interventions are not in scope for this service guideline. Training for families and carers needs to be in line with recommendations 1.7.1 and 1.7.2 of the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). However, we have made a recommendation (1.2.7) about staff working with people with a learning disability and behaviour that challenges having access to speech and language therapy when needed.
Royal College of Speech and Language Therapists	Short	17		1.4.3	Although this section already mentions the need of having a speech and language therapist in team, we believe it should also identify the need (for speech and language therapist) to have links with specialist AAC services	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met.
Royal College of Speech and Language Therapists	Short	20	18	1.4.15	We question whether you should include links here, to the forensic competency document (in draft – HEE)? Are there links made elsewhere in the document that refer to the NHSE TC Service Specification document?	Thank you for your comment. We have referenced the Transforming Care Service Specifications in the background section of the guideline.

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Royal College of Speech and Language Therapists	Short	21	10	1.5.5	We believe that relational support, person centred care, therapeutic input, and culture of the organisation and values of staff are of greater significance than the number of beds in a service.	Thank you for your comment. The Guideline Committee agree that numbers of people does not guarantee greater quality of service or quality of life and it was more important that people had a choice over where they lived, that the type if accommodation offered was based on their needs and preferences and offered a choice over who they lived with. The research evidence suggested that there were no greater economies of scale over 6 people but that there was weak evidence supporting one type of accommodation over another, in light of the lack of robust evidence for a specific number of residents being optimum to maximise choice, control and wellbeing, or being more effective or cost effective, the reference to a specific number has been deleted. The Guideline Committee favoured accommodation, which offered security of tenure and a split between supported service provision and accommodation.
Royal College of Speech and Language Therapists	Short	22	9	1.5.8	The RCSLT would like to clarify that communication needs are considered as part of considering a person's health and well-being both in relation to the person understanding and being involved in a process and in terms of recognising and addressing pain and discomfort as outlined in standard five of the Five Good Communication Standards.	Thank you for your comment. We agree that communication needs are necessary when considering a person's health and wellbeing. We have revised recommendation 1.2.21 to read: 'In all settings, staff working with children, young people and adults with a learning disability and behaviour that challenges (and their families and carers) should reduce the risk of behaviour that challenges developing by: • identifying health or sensory problems early • providing strategies and interventions to increase communication'. Earlier in the guidelines we recommend that all staff working with children, young people and adults with a learning disability and their families should find out their information and communication needs, record them and share this information with everyone working with them in line with the Accessible Information Standard. This recommendation is relevant throughout the guidelines, not just for health checks.
Royal College of Speech and Language Therapists	Short	25	17	1.8.1	'…considered and exhausted' – we suggest adding 'in a timely manner that does not further contribute to the crisis.'	Thank you for your comment. This recommendation has been revised accordingly.
Royal College of Speech and Language Therapists	Short	25	20	1.8.2	Using the MCA where applicable to consider best interests	Thank you for your comment. The guideline references the Mental Capacity Act 2005 where applicable.
Royal College of Speech and Language Therapists	Short	28	3	1.9.3	We believe it would be useful to address awareness within team around trauma, attachments and personality issues here also.	Thank you for your comment. The Guideline Committee agrees that people working with people with a learning disability and behaviour that challenges should be aware of these issues. The Positive behaviour support competence framework that we referenced and linked to in recommendations 1.9.2 and 1.9.3 includes being aware of adverse life events and experiences that may impact or be a factor in the function of a person's behaviour. We have also revised recommendation 1.2.5 in Enabling Person Centred care that support should • take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems, and their life history.
Royal College of Speech and Language Therapists	Short	6	9	How does it relate to legal duties and other guidance?	We wonder whether the Autism Act & NICE Autism guidance also be included here?	Thank you for your comment. We have revised this text to add the Autism Act 2009. The NICE guidelines for autism NICE (2012) Autism spectrum disorder in adults: diagnosis and management. Clinical guideline (CG142). will be referenced in the recommendations where appropriate
Royal College of Speech and Language Therapists	Short	7	11-17	Aims and principles	The RCSLT suggest an explicit reference to communication is needed to achieve these, for example: "recognise and make reasonable adjustments to meet people's communication needs"	Thank you for your comment. We have added reference to the Accessible Information Standard in recommendation 1.2.6. We have added the reference and hyperlink to the Accessible Information Standard to the list of relevant legal duties and guidance.

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Royal College of Speech and Language Therapists	Short	9	31	1.1.7	We believe that the term 'least restrictive' is more suitable here. Sometimes, care and support for the person may need to be restricted further to maintain safety for themselves and for others.	Thank you for your comment. The Guideline Committee agreed this wording to indicate that some restrictions may need to be in place but that risk management should not increase these.
Sirona Care and Health		10	13	1.1.8	We are not sure that "contact time with specialist professionals" would be the best measure of outcome of interventions. Perhaps it would be better to have evidence of a PBS plan being in place and implemented. If the aim is to monitor involvement/contact with specialist professionals, perhaps look at number of referrals to the team. Direct contact time would not pick up the extensive consultancy, liaison and staff training that is part of working with challenge.	Thank you for your comment. The Guideline Committee thought it useful to include this as one example of evidence, given their experience that specialist practitioners can be highlighted by a service as an indicator of its quality when, in practice, people who need support may have only very limited contact time with these practitioners.
Sirona Care and Health	Short	10	8-10	1.1.8	The outcome measures mentioned aren't adapted for use with people with a LD and are more of a carer outcome measure. Could quality of life measures be considered?	Thank you for your comment. This recommendation has been updated to include reference to quality of life ratings, as suggested. It also now references quality checks by user organisations and quality review visits from community learning disability teams.
Sirona Care and Health	Short	11	General	1.2	We think that the Positive Behaviour Support framework should be mentioned in this section (1.2) more explicitly as the PBS competency framework is mentioned later as a tool for measuring skills of staff. Sirona Care and Health	Thank you for your comment. We mean 'behaviour support' to be a generic term for behavioural interventions that are in line with the evidence based interventions recommended in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). This guideline seeks to complement rather than replicate the clinical guideline which focuses on prevention, management and treatment of challenging behaviour.
Sirona Care and Health	Short	12	22	1.2.9	There is an assumption in this point and throughout the document that social workers are integrated within health teams and these make up the community learning disability team. In our local area social workers are not within the CLDT. We question whether it is viable/realistic for social workers to take on the role of "named workers" as they do not tend to be involved with cases long term. We wonder whether the role of "named worker" could be held by others in the CLDT, such as nurses or behaviour support practitioners. However, it is also not viable for this to be a permanent role in the CLDT as service users are opened for episodes of care then closed once the work is complete.	Thank you for your comment. We have revised the recommendation to make it clearer about how local authorities, clinical commissioning groups and service providers need to work in partnership to coordinate care and support. We have provided an additional example of a health practitioner as the named care coordinator. We have also revised the recommendation to say that care and support needs to be coordinated over the long term.
Sirona Care and Health	Short	13	18	1.2.13	This line refers to staff with "specific skills" matched to the person. If this is to refer to social workers, this may not be possible when the person is allocated a generic social worker as in our local area.	Thank you for your comment. This recommendation does not relate to social workers specifically. The Guideline Committee is aware that this may not be possible in all instances, but thought it important to recommend and highlight best practice, based on the research evidence. The committee consider the recommendation to be aspirational but achievable.
Sirona Care and Health	Short	15	2	1.3.1	Need to include psychiatry, nursing, physiotherapy and dietetics here. There is a need to reflect a multi-professional approach rather than single professions, and multi-disciplinary team formulations.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Sirona Care and Health	Short	15	8	1.3.1	This line refers to restrictive interventions. Restrictive interventions may include physical restraint but in our local area the CLDT does not offer training on the use of restraint. So there would be a need to think about what service would offer this training.	Thank you for your comment. We have revised the recommendations that list the specialist services that should be made available to providing support. Individual interventions are not in scope for this service guideline but we have referenced the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).for interventions where appropriate. We say in recommendation 1.3.5 that training for families and carers needs to be in line with recommendations 1.7.1 and 1.7.2 in the clinical guideline that accompanies this service guideline

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						(Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Sirona Care and Health	Short	17	16	1.4.2	Crisis response and interventions could highlight use of mainstream services, linking in the mental health crisis teams.	Thank you for your comment. We agree. Several of the recommendations in the guideline suggest how services should work in partnership or together. Recommendation 1.4.10 about intensive behavioural support during a crisis says that the response should 'involve partnership with other commissioners, service providers and family members and carers'. We hope that the emphasis on partnership working in the guideline will allow more linking of services and team around the person.
Sirona Care and Health	Short	17	17	1.4.3	We agree with the importance of links between local authorities, ccg and CLDT.	Thank you for your comment and support for the guideline.
Sirona Care and Health	Short	19	8 17	1.4.8- 1.4.9	In our CLDT we provide an initial assessment contact within 4 weeks and aim to complete behaviour assessment within 12 weeks, which is much less than the 18 week criteria. Response to crises is from the CLDT within working hours and from on-call Psychiatry out of hours. We see this as sufficient to respond to crises as they arise and to provide a quick response.	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems and to provide a face to face response within 4 hours if that is what is needed. We have revised recommendation 1.4.9 which now reads that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support.
Sirona Care and Health	Short	21	10	1.5.5	We feel this principle is sound but would not be viable without a robust funding strategy as these placements are expensive. Units in our local area are often larger than 3 residents.	Thank you for your comment. The Committee agreed on the importance of accommodation as a determinant of health and wellbeing. There was not strong evidence to support the recommendation of one type of accommodation over another, or the maximum number of residents to maximise choice, control, and wellbeing. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, homelike environments with people having a choice over who they live with. However, in light of the lack of robust evidence for a specific number of residents being optimum to maximise choice, control and wellbeing, or being more effective or cost effective, the reference to a specific number has been deleted. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Sirona Care and Health	Short	6	13	Aims and principles	It is good that there is reference to the daily activities that people "want to do" but this can be an area of conflict if family or carers feel that the person should be doing more.	Thank you for your comment. The Guideline Committee considered family involvement in a person's care and support was very important, if this is possible and this is what the person wanted. The Guideline Committee felt that families bring helpful insights to the person's strengths, abilities and personality as they know him or her well and this will support staff working with that person.
Sirona Care and Health	Short	8	15	1.1.3	We like the idea of pooled budgets for health, social care and education to develop local and regional services. However, locally we moved away from a pooled budget and integrated working between health and social care when social care moved to generic working (i.e. all social workers now work with people with all different needs, not just people with learning disabilities). It would be beneficial to be more integrated but again very challenging to implement within the current service models in our area.	Thank you for your comment. The committee considered current practice and good practice in developing the recommendations. It was important to the Guideline Committee that services should have the specific skills and experience to work with people with learning disabilities and behaviour challenges and their families. They agreed this recommendation was aspirational but achievable.
Sirona Care and Health	Short	8	3	1.1.1	We agree that it would be helpful to have a knowledgeable lead commissioner for challenge who is responsible from cradle to grave. However, this could be very challenging to implement due to the move to a very large CCGs commissioning numerous companies to deliver specialist support for people with an LD and that adults and childrens services are not currently commissioned together.	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Sirona Care and Health		9	17	1.1.6	We are not sure how a single point of access would work in our local area as health and social care teams are separate, and there are different services for children and adults.	Thank you for your comment. The Guideline Committee sees the role of the lead commissioner as spanning health and social care. We have revised recommendation 1.1.1 to read: 'Local authorities and clinical commissioning groups should jointly designate a lead commissioner who has overall responsibility for strategic commissioning of health, social care and education services specifically for

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						children, young people and adults with a learning disability, including for those whose behaviour is described as challenging and those at risk of developing behaviour that challenges'.
Sirona Care and Health		9	27	1.1.7	Whilst the responsibility for managing risk can be jointly held between commissioner and provider, risk assessment and management plans could be developed in consultation with specialist professionals within the CLDT.	Thank you for your comment. This has been edited to include reference to working with other organisations, to reflect that the people involved will vary depending upon the specific situation and context. We have revised recommendation 1.4.8 to include assessments of both need and risk. Specific risk assessments are referenced in section 1.5.7 on risk assessment in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have referenced the clinical guideline where appropriate.
Sirona Care and Health	Short	General		General	Overall we felt this is a useful document with many recommendations that could be easily implemented.	Thank you for your comment and support for this guideline.
Sirona Care and Health	Short	General		General	Commissioning of individualised services is really important – we are really struggling as we find that social care and CHC when finding placements are trying to slot people into places a provider has rather than building a service around the person (a longer term perspective). There needs to be some creativity in commissioning services that can allow for building a service around a person. Some direction on this within the guidelines for commissioners would be helpful.	Thank you for your comment. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
Sirona Care and Health	Short	General		General	Whilst we agree with the need to support parents and carers and involve them fully in the process, it would be helpful to have some guidance on how commissioning could support specialist services when the specialist assessment and advice is not accepted by parents /carers (often interventions require changes to the way people support/communicate with the person and be offered more choice and control - sometimes parents want a more medical intervention for example). Thus the person does not receive the support that would probably help them but it does not seem appropriate to take this down a safeguarding route. This is particularly difficult when the person is an adult living at home.	Thank you for your comment. The Guideline Committee felt strongly that it was important to work in partnership with families and carers in supporting them in their day to day care. We hope that the recommendations in the guideline will highlight best practice, based on the research evidence for the person with a learning disability and behaviour that challenges, their families and service providers. The Guideline Committee consider the recommendations to be aspirational but achievable.
Sirona Care and Health	Short	General		General	We think commissioners should be ensuring that providers in the area have clear training strategy for staff in PBS and that support staff are paid extra as they will be expected to have the competencies expected. We think it would be helpful for providers offering placements for people who challenge to have a clear expectation of the qualifications and approaches. Anecdotal evidence suggests that providers often say they are doing PBS but are not necessarily implementing it effectively.	Thank you for your comment. After careful consideration the Guideline Committee feel that the responsibility of service providers to ensure that their staff have the right skills and competencies to deliver care and interventions, in line with the accompanying clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) is adequately expressed in the recommendation 1.9.1. A hyperlink to the clinical; guideline has been included for people who wish to know more in detail. We have also included the Positive behaviour support competence framework. at direct level contact and consultant level in recommendations 1.9.2 and 1.9.3 and have included a hyperlink to the framework for more information. While it is not in NICE remit to recommend funding and staff remuneration, we hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. The Guideline Committee's view was also that investment in the interventions recommended here would lead to savings elsewhere in the system.
Stay Up Late	Short	11	14	1.2.3	we'd like there to be an acknowledgment that it's also important for people to be able to choose who they live with if they are living in a group situation (and perhaps to remember that generally most people choose to live alone, or with their partner, group living is unusual outside of student life).	Thank you for your comment. We agree that people should have a choice on where they live and who they live with. We have revised recommendation 1.5.5 to say 'Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them' and in recommendation 1.5.6 'If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of sharing housing with other people. This should be with a small number of other people and in a setting that is of usual domestic size, and with a home-like feel. Involve people in choosing how many people, and who they live with'.
Stay Up Late	Short	12	10	1.2.7	we'd like there to be a mention that it's also really important that people are enabled to be actively involved in recruiting the right support staff for them	Thank you for your comment. We agree that it is important that people are involved in the recruitment of staff. This is covered in recommendation 1.9.6.
Stay Up Late	Short	13	2	1.2.11	Care and support planning Could there be a mention of the need to focus on 'community connecting' and developing support in a localised and natural way	Thank you for your comment. The Guideline Committee agree that localised approaches to care and support are essential. Whilst no evidence was found in relation to localised care and support planning

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						specifically, the committee included localisation as an overarching principle of service design. Please see the section entitled 'Aims and principles' for more information.
Stay Up Late	Short	13	18	1.2.13	we'd like to see that person with a learning disability is also seen as a key person in this process	Thank you for your comment. The Guideline Committee agree that people with a learning disability and their families, friends, and carers should be involved in this process. After careful consideration, we think that this is covered in recommendations 1.2.4 and 1.2.13.
Stay Up Late	Short	14		general	Some mention of need to develop a pro-active approach and being cautious about support that may actually serve to exclude people from their communities. So strategies being put in place that recognise the difficult behaviour but a positive focus on working through the difficulties	Thank you for your comment. The Guideline Committee agree that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff.
Stay Up Late	Short	14	13	1.2.17	making sure that information is universally and explicitly clear for people who need support and carers could 'information' also be regarded as things like trying a new living arrangement for a few weeks to see what it's like. So thinking in non-conceptual ways about how people can make real choices	Thank you for your comment. We agree that information should be clear for everyone. We have revised recommendation 1.2.6 to refer and hyperlink to the Accessible Information standard and added this to the list of relevant legal duties and guidance. We do not have research evidence on whether trialling services for a period of time lead to better outcomes for people. The Guideline Committee agreed that the level of detail in this recommendation would suffice on the basis that the guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation.
Stay Up Late	Short	16	28	1.3.4	as well as a 'welcome pack' we think it's important that on-going information is provided through peer groups etc (a lot can get forgotten, be overwhelming or be tucked in the back of a drawer at the start)	Thank you for your comment. We agree that ongoing support is important. We have included 'peer support' as a type of support in recommendation 1.3.2. We have also revised recommendation 1.3.4 to include support from first contact onwards.
Stay Up Late	Short	21	10	1.5.5	(same as 1.2.3 and needing to be able to choose house mates)	Thank you for your comment. We have revised the recommendation as you have suggested.
Stay Up Late	Short	22	1	1.5.8	could there be a system of external input be introduced for the support team if someone becomes challenging to support? As a way of investigating possible causes of their behaviour and providing coaching support to the team	Thank you for your comment. This recommendation has now been moved to the enabling person-centred support section (now recommendation 1.2.23). All staff working with people with learning disabilities and behaviour that challenges should be able to refer appropriately or access specialist services when needed. More information on this is in section 4 on 'Services in the community- – prevention, early intervention and response' and section 1.9 Staff skills and values.
Stay Up Late	Short	25	13	1.8	we don't know enough to comment on this, however, we don't want our non-comment to be seen as an endorsement of the ATU system. We stand by the advice of professionals who say that all support can be provided in a community setting.	Thank you for your comment. This section relates to how to use inpatient admissions in an appropriate way, with an emphasis on people returning home as soon as possible.
Stay Up Late	Short	27	14	1.9	We'd like to see an emphasis on need for involvement in selecting and recruiting staff by people getting the support. We think this should also extend to recruiting staff where there is some sort of shared interest/affinity with the people being supported so as to create richer support relationships.	Thank you for your comment. The Guideline Committee agree that the relationship between staff and the person and their families is an important aspect of involving the person and their family in the choice and control over their care. We have included involvement of the person, their family and carers in the recruitment of staff in recommendation 1.9.6. In recommendation 1.2.15 we talk about matching skills to the characteristics of the person they care for.
Stay Up Late	Short	28	11	1.9.6	We'd like to emphasise that involvement should be proper and meaningful for the individual. Not a system or tick-box approach.	Thank you for your comment. The Guideline Committee also felt that involvement should be meaningful and if the recommendations are implemented as intended, will achieve proper and more meaningful involvement in a person's care and support. To support this, the recommendation has also been revised to support involving children and young people in the recruitment of staff where possible.
Stay Up Late	Short	30		general	Putting the guidelines in to practice – we think it's key that health and social care support is properly integrated for the individual for this to happen.	Thank you for your comment. We have referred to NHS England in reference to the policy context of Transforming Care in response to the Transforming Care report: a national response to Winterbourne View Hospital (Department of Health 2012). The report calls on local authority and NHS commissioners to use integrated commissioning arrangements to transform care for vulnerable adults with learning disabilities and autism, and mental health conditions or behaviours described as challenging. This guideline takes into account the direction of travel in Transforming Care. It aims to complement this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges.
Stay Up Late	Short	31		general	We think it's important that there's a concerted effort to identify isolated families – including those without the in depth knowledge of the system and perhaps those who've simply run out of energy with it all.	Thank you for your comment. The Guideline Committee agree that it is important to make sure that people can access the information they need when they need it. The recommendation 1.3.3 suggests

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						that people should have access to information in public and universal services, such as the local authority website, local libraries and GP surgeries.
Stay Up Late	Short	32	general	Putting this guideline into practice	Develop and action plan Could you provide a questionnaire/resource/tool to help facilitate the creation of an action plan? Could action plans be shared (anonymously and publicly) so people can understand how individuals are navigating the process?	NICE routinely produce baseline assessment and resource impact tools. To encourage the development of other practical support tools, we run an endorsement scheme aimed at encouraging our partners to develop these, in alignment with NICE recommendations. Eligible tools are assessed and if successful, will be endorsed by NICE and featured on the NICE website alongside the relevant guideline.
Stay Up Late	Short	33	general	Research recs	Models of person centred support What does this mean in practice for the individual? We see there's quite a difference in expectations between providers who say they provide person centred support and the experiences of individuals who aren't receiving what they'd like. Are there any self-assessment tools available to teams to help with this? And how can staff challenge management cultures if they see the need for change but are stifled (as is often the case in our experience)	Thank you for your comment. The Guideline Committee agree that there is sometimes a mismatch between what providers say they provide person-centred support and the experiences of individuals who aren't receiving what they'd like. In this service guideline we hope that the recommendation directed to commissioners, based on the best available evidence of good practice will improve people experiences of services.
Sussex Partnership NHS Foundation Trust	Full	12	7-12	1.2.6-1.2.7	Should there be standards around inclusive communication and commitment to reasonable adjustments	Thank you for your comment. We have revised this recommendation to include reference to the Accessible Information Standard. The standard covers inclusive communication and reasonable adjustments to support people, carers and families with a disability, impairment or sensory loss to make use of health and social care services.
Sussex Partnership NHS Foundation Trust		15		1.3.1	There is no mention of psychiatry and it is not clear why this list is not as comprehensive as the list on page 17.	Thank you for your comment. Following stakeholder feedback we have removed reference to particular professional groups from recommendations 1.3.1 and 1.4.3 and instead focused on the needs that should be met. We hope this will allow for flexibility in the local workforce as to which professionals meet those needs. The focus of this guideline was on service design and delivery. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
Sussex Partnership NHS Foundation Trust	full	19	17	1.4.9	The guidance here is aspirational and we would agree with this in principal. It would be great to be able to provide this helpline and a 1 hour response at times of crisis but this would need significant investment for teams to be able to provide this. This would have significant implications for staffing levels and financially would be difficult to manage within existing resources. Unless recurring money was made available to develop this properly, we would prefer a model whereby we look to partner with services which already offer this out of hours provision. Review of cases often suggests that crises could be avoided by more resources being available before the crises is reached and by the development of good, robust and multi-agency owned contingency plans for individuals.	Thank you for your comment. We have revised the wording of the recommendation to be clearer and more realistic about response times. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. The committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system. The committee were mindful of the resource constraints on services. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
Sussex Partnership NHS Foundation Trust	full	24	23-30	1.7.1	Respite care - available at short notice, in crisis and to prevent a crisis Again there is a real need for this particularly for those people with more complex needs and particularly those who display behaviours that may challenge but there are not the services available to provide this and again this needs investment.	Thank you for your comment and support for the recommendation. The Guideline Committee was also concerned about the difficulties that can arise in accessing respite care. It hopes that the recommendations in this guideline will help advocate for the commissioning, or continued investment in, evidence-based services.

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Sussex Partnership NHS Foundation Trust	Full	General		General	We really welcome that there will be a single commissioner for CYP with LD and Adults and also that the guidance advocates the joint commissioning of specialised support. We also like the identification of contingency funds and encouraging commissioners to work together to develop services and the need to strengthen advocacy services.	Thank you for your comment and support for this guideline.
Sussex Partnership NHS Foundation Trust	full	general		general	Positive behaviour support competence framework This is really good to see i and is a good framework for measuring competency.	Thank you for your comment and support for this guideline.
Sussex Partnership NHS Foundation Trust	full	general		general	Consistent definitions of young person age Age range of young people the guidance refers to 13-17 but SEND refers to 0-24	Thank you for your comment. We have retained the definition for children and young people to be in line with the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
Sussex Partnership NHS Foundation Trust	Full	General		general	The guidance says staff should have access to specialists in communication but ideally families will have access to communication specialists too (although to be fair it does mention SALTS in services for CYP).	Thank you for your comment. We have revised the recommendations that list the specialist services that should be made available to providing support. Individual interventions are not in scope for this service guideline but we have referenced the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), where appropriate.
Sussex Partnership NHS Foundation Trust	full	general	general		Does more need to be said about the economic and social impact of supporting a person with LD at home and needs of services to be sensitive to needs of families, culturally aware and flexible – offering services out of 9-5 hours not just when a family is in crises. Also does more need to be said about challenging stigma and engaging people in meaningful daily activity / employment.	Thank you for your comment. The economic and social impacts of caring were considered during guideline development, particularly in the economic analysis.. We looked for economic evidence if it was there and considered them with the Guideline Committee If there were no economic evidence, then the GC had their own discussion which informed the recommendations. We did not have any evidence on the costs and benefits of offering services outside of normal office hours. The resource impact team considered that the provision of intensive support during a crisis would likely incur costs to implement. They also said that implementing the guideline may also results in the following benefits and savings: lower rates of placement breakdown due to effective respire care and suitable housing. The unit cost per case of £31, 296 for a crisis resolution team for adults is taken from the unit costs of health and social care 2017. Lead commissioners will need to have 24/7 multi-disciplinary crisis support, and services should be developing in this way to meet the requirements of the Transforming Care agenda. The Guideline Committee's view was also that investment in the service recommended here would lead to savings elsewhere in the system. The overarching principles state that services should respect people's cultural, religious and sexual identity and help people to take an active part in all aspects of daily life. Recommendation 1.4.4 recommends that services should be flexible and responsive. Recommendation 1.2.23 has been amended to make reference to involvement in employment.
Sussex Partnership NHS Foundation Trust	full	general	general	1.1.5	Planning and Delivering Services to local need I think this should reference the role of the Heathy Child Pathway to identify children with LD and CB who are in need of support Also the need for the Local offer to identify the reasonable adjustments which universal services need to make to meet the needs of children with LD including for behaviour which challenges	Thank you for your comment. This guideline takes into account the direction of travel in Transforming Care. It aims to complement this work by providing evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. Recommendation 1.4.10 states that there should be local, personalised response to children, young people and adults who need intensive support during a crisis and these services made known in the local offer. In recommendation 1.7.1 the local offer should also include information on short breaks.
Sussex Partnership	full	general	general	1.1.8 – 1.1.11	Quality Assurance This needs strengthening – need clear Quality assurance framework linked to KLOE and including things like children's rights to a childhood and the	Thank you for your comment. To take into account stakeholder consultation feedback, recommendation 1.1.10 has been updated to include reference to quality of life ratings, as suggested. It also now

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NHS Foundation Trust					implications for universal services and the local offer – I worry that commissioners could performance manage local providers without the appropriate levels of commissioning I like the 9 principles in the attached doc and feel this could lend itself to informing a quality assurance framework	references quality checks by user organisations and quality review visits from community learning disability teams.
Sussex Partnership NHS Foundation Trust	full	general	general	Aims and principles	Aims and principles Seems a bit adult focussed (I know there is a lot of reference to children and young people later in guidance) I wonder if it should change promote person centred care to Promote person centred and family centred care? Also should there be some reference to the need for collaborative care models where multi-agency support is built around the needs of individuals?	Thank you for your comment. The Guideline Committee agree that using the term 'people' risked being assumed to mean adults only. For this reason the use of the term has been changed throughout to state children, young people and adults where the recommendations is applicable to all people and ages. We have referred to multi agency teams working in partnership with the child, young person or adult and their family in a number of recommendations: 1.1.12, 1.6.5 and 1.6.7.
The Challenging Behaviour Foundation	Short		12	1.1.8	Change "restraint" to "restrictive practices, such as restraint, seclusion, overmedication"	Thank you for your comment. The wording has been edited to 'restrictive interventions' to respond to your comment.
The Challenging Behaviour Foundation	Short		12	1.3.5	Specify what is meant by 'specialist behaviour support'	Thank you for your comment. We mean 'specialist behaviour support' to be a generic term for behavioural interventions that are in line with the evidence based interventions in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
The Challenging Behaviour Foundation	Short		12-17	1.2.12	Stress that holistic assessment of the 'person' – e.g. strengths and difficulties, motivations and interests is essential to good PBS planning	Thank you for your comment. NICE guidelines aim not to duplicate guidance which is provided elsewhere. Assessment of challenging behaviour and the development of behaviour support plans are covered in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
The Challenging Behaviour Foundation	Short		13-20	1.2.8	Should LAs seek evidence how services have sought the views of the 'person' and their family, and how these have been acted on	Thank you for your comment. We have aimed to balance these considerations in the wording of the recommendations about quality assurance.
The Challenging Behaviour Foundation	Short		16	1.2.3	Add – enables the child, young person or adult to be consulted appropriately about their wishes, making adjustments to do so (e.g. as required by the Children and Families Act)	Thank you for your comment. We have added a recommendation 1.2.6 which states: Staff working with children, young people and adults with a learning disability and their families should find out their information and communication needs, record them and share this information with everyone working with them in line with the Accessible Information Standard to enable people to fully participate in communicating their needs and wishes, We have said in recommendation 1.2.2 that people should be actively involved in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the Mental Capacity Act 2005.
The Challenging Behaviour Foundation	Short		20		Need to specify how children in residential school placements can be known to and receive support from local services	Thank you for your comment. Recommendation 1.6.4 has been amended to make clear that children in residential placements should also receive support from health, mental health and behaviour support practitioners.
The Challenging Behaviour Foundation	Short		23	1.2.14	Specify what is meant by 'strategies and interventions'. Specifically mention acknowledged good practice e.g. positive behaviour support	Thank you for your comment. The focus of this guideline is on service design and delivery. Further detail on interventions and strategies that could be used are detailed in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
The Challenging	Short		29	1.8.10	Specify what is meant by a 'specialist in behaviour that challenges'.	Thank you for your comment. We have revised this definition and removed the term when used as a profession title. We have kept the term "behaviour support" to be a generic term for behavioural interventions that are in line with the evidence- based interventions recommended in the clinical

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Behaviour Foundation						guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
The Challenging Behaviour Foundation	Short		6		Safeguarding referrals	*Query – not clear which page or section referring to.*
The Challenging Behaviour Foundation	Short		9	1.4.9	Should there also be 'safe spaces' – as an alternative to accident and emergency departments or police custody – to promote de-escalation / unnecessary use of the Mental Health Act	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We did not find research evidence on the use of "safe spaces", however, we hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system or inpatient admission due to the lack of available specialist support in the community.
The Challenging Behaviour Foundation	Short	1	6 onwards	Who is it for	Who is it for? This guidance would also be useful for Care and Treatment Review Independent Panel Experts (especially for Community CTRs and CETRs) Commissioners and providers of support for carers The police (who are often called to manage crisis situations in services). Families are also advised to call the police if challenging behaviour escalates.	Thank you for your comment. We understand the CTRs and CETRs independent review panel of experts should include an expert by experience, who is a person with a learning disability or autism or a family carer with lived experience of services. The panel also includes a clinical expert who is qualified to work in healthcare and the commissioner who pays for the person's care, so will include professionals, people with lived experience and commissioners we have listed as people this guideline is relevant for. We have included the criminal justice agencies in the section on who is this also relevant for.
The Challenging Behaviour Foundation	Short	10	1	1.1.8	How do these new QA measures relate to the role and work of the CQC? Who is ultimately responsible to respond to findings appropriately?	Thank you for your comment. This recommendation includes a range of suggestions for how outcomes could be measured, rather than an exhaustive or prescriptive list. These are intended to help commissioners rather than to replace Care Quality Commission (CQC) measures.
The Challenging Behaviour Foundation	Short	10	14	1.1.8	Specify what is meant by 'experts by experience' – e.g. required specific experience and competencies of 'experts by experience', their training and support, who they report to and the outcome of their involvement? This term is now used by different organisations meaning different things (e.g. CQC, NHSE for CTRs, service providers etc.) With regard to expert by experience quality assurance in inpatient services (please also see l. 16-18), Specify that the experience must be relevant and appropriate	Thank you for your comment. 'Expert by experience' is included in the 'Terms used in this guideline' and was the Guideline Committee's preferred term for people with lived experience of using services for people with learning disabilities and behaviour that challenges including people with a learning disability themselves and their family members and carers.
The Challenging Behaviour Foundation	Short	10	16-18	1.1.9	How does this relate to the CTR process? Inpatient services should also evidence they have captured the 'voice' of the person and their family, that their views have been listened to and acted on. There is also a need for services to evidence how they work collaboratively with the person's family and how they facilitate family relationships to continue? There is a danger that the person and their family are considered as less important than the Expert by Experience and this needs to be addressed and clearly stated	Thank you for your comment. Recommendation 1.1.12 directs the commissioner to require service providers to show evidence of achieving specified service outcomes to indicate quality of service. These indicators and others may also be used by Care and Treatment reviews when deciding whether a person needs to stay in an assessment and treatment unit. We have included sources of evidence from experts by experience to show evidence of capturing the voice of the person and their family. We have also included evidence of stability of placement and continuing education for children and young people as indicators of quality. We have revised recommendation 1.1.13 to read: "Service providers should use evidence gathered to continuously improve services. They should record the results and make them available to people who use services, and their families".
The Challenging	Short	10	19	1.1.10	Does this include families? need to be clear it does	Thank you for your comment. 'Expert by experience' is defined in the 'Terms used in this guideline' section and includes family members and carers.

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The Challenging Behaviour Foundation	Short	10	23-25	1.1.11	Strengthen the wording here as it appears too vague to be helpful. Specify the meaning of 'record the results' and 'make them available'?	Thank you for your comment. The Guideline Committee used the wording 'to continuously improve services' to demonstrate the intended aim of this recommendation. The recommendation includes the wording 'make them available to people who use services, and their families' to emphasise the importance of services being accountable to experts by experience for their continuous improvement work.
The Challenging Behaviour Foundation	Short	11	11-13	1.2.2	This guidance applies to under 18s and wording here needs to reflect that.	Thank you for your comment. We have revised all recommendations to read 'children, young people and adults' if this is what is meant.
The Challenging Behaviour Foundation	Short	11	14-27	1.2.3	1. Need to include listening to families. 2. Should also spell out how the support given should protect and respect a person's human rights E.g. right to privacy and family life 3. Need to mention specific good practice – e.g. use communication-friendly strategies, functional assessment of behaviour and positive behaviour support plan	Thank you for your comment. We agree that listening to families is important and this is reflected in the recommendation 1.2.1 that says: "practitioners working with children, young people and adults with a learning disability and behaviour that challenges and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services". For specific evidence based approaches we reference the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have also added the Human Rights Act to the list of relevant legal duties and guidance as this is relevant to the whole guideline. Rather than include the detail of all publications suggested as useful to signpost, we have updated the introduction to explain how our recommendations build on, rather than replicate, existing guidance and legislation.
The Challenging Behaviour Foundation	Short	11	27	1.2.3	'continuity of relationships' - specify exactly what this means and how this can be done, E.g. encouraging and supporting family visits and visits home	Thank you for your comment. We did not find research evidence specifically on effective ways of making sure services promote continuity of relationships. After careful consideration, we feel that the level of detail in this recommendation would suffice on the basis that the guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation.
The Challenging Behaviour Foundation	Short	12	10-12	1.2.7	Strengthen the wording here as it appears too vague to be helpful. Specify what 'access to' and 'specialists in communication' mean e.g. specialist Speech and language Therapist advice? In-house Speech and Language assistant? Staff have a certain level of basic training?	Thank you for your comment. We have revised this recommendation to say: All staff working with people with a learning disability and behaviour that challenges should have access to speech and language therapy when needed.
The Challenging Behaviour Foundation	Short	12	15	1.2.8	'think about offering it whenever it is needed' Suggest remove 'think about'. Should LAs seek evidence of how services have sought the views of the 'person' and their family.	Thank you for your comment. The strength of wording in the recommendation reflects the existing legal duties and the strength of the research evidence. The recommendations on advocacy were based on Guideline Committee consensus on good practice, and the strength of the wording reflects this.
The Challenging Behaviour Foundation	Short	12	22-24.	1.2.9	This person must have knowledge and understanding of learning disability and behaviour described as challenging	Thank you for your comment. We agree with your comment. We have revised recommendation 1.2.10 to include that the named worker should get to know the person and their needs well. In recommendation 1.9.1 we cover the skills and knowledge that staff providing support to children, young people and adults need. This includes reference to following the general principles of care section of the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11), that covers 'understanding learning disabilities and behaviour that challenges'.
The Challenging Behaviour Foundation	Short	12	25	1.2.10	Specify what is meant by 'regular meetings'?	Thank you for your comment. The frequency of meetings has not been specified as it may differ for each person.
The Challenging	Short	12	8	1.2.6	Specify what is meant by 'information needs'	Thank you for your comment. We have revised this recommendation to strengthen the wording by making reference to following the Accessible Information Standard.

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Behaviour Foundation					'share' – strengthen wording –e.g. ensure staff understand these and receive appropriate training in how to support them	
The Challenging Behaviour Foundation	Short	13	1-10	1.2.11	There needs to be specific reference to acknowledged best practice is needed here – e.g. communication-friendly strategies, functional assessment of behaviour, positive behaviour support	Thank you for your comment. We reference best practice in relation to the evidence based interventions in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). The clinical guideline also provides guidance on how to carry out a functional assessment (see recommendations 1.5.9–1.5.11 of the clinical guideline). In addition, recommendation 1.2.14 covers the requirements of the behaviour support plan.
The Challenging Behaviour Foundation	Short	14	3-8	1.2.15	Also include when reviewing 'people's' plans – Seek the views of the 'person' and their families and take these into account	Thank you for your comment. A cross reference to recommendations 1.2.1 to 1.2.4 about involving people and their families has been added to this recommendation.
The Challenging Behaviour Foundation	Short	14.	1	1.2.15	Example of "placed out-of-area" isn't a good one here. If the person has been placed out-of-area it should have only have been after significant discussions and reviews anyway!	Thank you for your comment. Out-of-area placement was identified by the Guideline Committee as an important time for review.
The Challenging Behaviour Foundation	Short	15	14	1.3.3	For children this is a requirement of the "Local Offer" which should be referenced. For adults, need to reference Care Act duties of local areas.	Thank you for your comment. We agree it is useful to highlight how the guideline relates to other guidance and legislation and have added a cross-reference to the Care Act 2014/other legislation throughout as per your suggestion. The Guideline Committee thought in this instance the wording is sufficient.
The Challenging Behaviour Foundation	Short	15	general	1.3	There needs to be greater emphasis on prioritising INVESTING in families as VALUED PARTNERS. We know that families are commonly "left to get on with it" until they reach crisis. There is an opportunity here to reinforce the early intervention and prevention approach, as well as to stress the need to invest in families, value them as key partners and acknowledge their long term commitment	Thank you for your comment. Following stakeholder feedback, we have strengthened several of the recommendations related to early intervention and prevention. In the aims and principles section we have revised the wording to say 'the guideline aims to help local areas rebalance their services by shifting the focus towards prevention and early intervention, and enabling people to live in their communities and increasing support for families and carers'. We have also strengthened the wording and labelling of sections 1.3 on 'support for families and carers' and section '1.4 - services in the community' to reinforce the early intervention and prevention approach
The Challenging Behaviour Foundation	Short	15	general	1.3	There needs to be clarification of what rights parents can expect to have in best case scenarios and establish exactly on what grounds these can be removed. This guidance should ensure it protect the rights of the 'person' rather than the 'service' For example, many parents report feeling 'bullied' by hospitals, such as visits being restricted if they have asked 'difficult' questions.	Thank you for your comment. Recommendation 1.3.5 includes advising family members about their right to, and explaining how to get, for example, 'support in an emergency and who to contact' and 'local safeguarding procedures and how to raise safeguarding concerns or make a complaint'.
The Challenging Behaviour Foundation	Short	16	11	1.3.5	Accessible, practical and timely information and access to training that will support their caring role and understanding of behaviour.	Thank you for your comment. We agree that people should be available to access the right support when they need it. Training for carers is in scope for the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) and we have provided a reference and hyperlink to the clinical guidelines for people who wish to know more.
The Challenging Behaviour Foundation	Short	16	8	1.3.5	Strengthen 'regular offers of support' wording. Also evidence that they have done so.	Thank you for your comment. We have revised the recommendation to include evidencing the offers of support. The strength of wording in the recommendation in relation to 'regular offers of support' reflects the existing legal duties and the strength of the research evidence.
The Challenging Behaviour Foundation	Short	17	17	1.4	Consider the development of standards and audit tool for these services to evaluate their practice against in order intervene early and prevent crises	Thank you for your comment. NICE routinely produce baseline assessment and resource impact tools. To encourage the development of other practical support tools, we run an 'endorsement scheme' aimed at encouraging our partners to develop these in alignment with NICE recommendations. Eligible tools are assessed and if successful, will be endorsed by NICE and featured on the NICE website alongside the relevant guideline.
The Challenging	Short	17	19	1.4.3	Add "and families" after people	Thank you for your comment. In this case we have retained the text, as it is directed at local authorities and commissioners of services and children, young people and adults with learning disabilities as this is the eligible criteria for access to learning disabilities teams and conclude the recommendation by saying

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Behaviour Foundation						how this can be achieved "This could be achieved by employing practitioners within the community learning disability team or by developing close links with practitioners in other relevant services." Recommendations in section 1.3 relate to supporting families more directly.
The Challenging Behaviour Foundation	Short	17	6	1.4.2	Specify how services can intervene early and prevent crises, and include investing in families here Eg. See below:	Thank you for your comment. This is covered by the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11).
The Challenging Behaviour Foundation	Short	17	7	1.4.2	Specify what is meant by 'develop capacity'	Thank you for your comment. Recommendations 1.4.1 and 1.4.2 provide further specificity on developing community capacity.
The Challenging Behaviour Foundation	Short	18	17	1.4.5	Do community 'forensic teams' have understanding of learning disabilities? Should the LD team work in partnership with the forensic team to ensure 'reasonable adjustments' are made and to ensure any forensic strategies / interventions can be effective?	Thank you for your comment. We do envisage that community forensic teams have understanding of learning disability. This can be achieved as a specialism within an existing team, for example a community learning disability team, or a learning disability specialism within a community forensic team. We hope that the recommendations, if implemented, will encourage greater collaboration between services to deliver service in line with the good practice in this guideline.
The Challenging Behaviour Foundation	Short	18	17	1.4.5	Signpost specifically which 'evidence based' interventions are intended here.	Thank you for your comment. We did not review evidence about the effectiveness of particular therapeutic interventions. The clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) considered interventions.
The Challenging Behaviour Foundation	Short	18	21	1.4.6	Specify what is meant by 'good communication'. As police are more and more frequently called when a 'person' reaches crisis point, there is a need for more specific and meaningful support for them – e.g. training? Also stress the importance of listening to families in order to de-escalate crisis situations. Also a need to develop crisis-support service to prevent 'people' coming into contact with criminal justice system in the first place.	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face to face response within 4 hours if that is what is needed. We hope that the implementation of this recommendation will reduce the inappropriate involvement of the criminal justice system due to the lack of available specialist support in the community.
The Challenging Behaviour Foundation	Short	19	10	1.4.9	There may be a need to differentiate between children and adults here. For children, need to ensure continuity of education for example. Also see point above.	Thank you for your comment. We have revised this recommendation to say that the crisis response should also give people clear contact details for children's services (as set out in the Local Offer) and adults' services.
The Challenging Behaviour Foundation	Short	19	29-30	1.4.10	And 'inform early intervention and prevention services and support'	Thank you for your comment. We agree and this is in line with stakeholder feedback. We have revised the wording of the recommendation to include this point.
The Challenging Behaviour Foundation	Short	19	8	1.4.8	Is '18 weeks' an acceptable waiting time for interventions given the level of need? This does not equate with the early intervention message this guideline should be promoting!	Thank you for your comment. We agree that that families should access the right support at the right time. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adult who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems and to provide a face to face response within 4 hours if that is what is needed. We have revised Recommendation 1.4.9 which now reads that the lead commissioner should set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support.
The Challenging Behaviour Foundation	Short	2	3	Who is it for?	Children, young people and adults with behaviour that challenges are the very last bullet in this list – this needs to be reconsidered. Suggest place it very first in the list to reflect the importance of placing the person at the centre of their care and the respect they should be accorded. Also to acknowledge the important role of families as the people who know and love the person best.	Thank you for your comment. We have revised this as you suggested to place children, young people and adults with behaviour that challenges first in the list of people the guidelines is also relevant for.

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The Challenging Behaviour Foundation	Short	20	12	1.4.13	And with their families?	Thank you for the comment. The Guideline Committee's view is that the wording in the recommendation is sufficient.
The Challenging Behaviour Foundation	Short	20	21	1.5.1	Commissioners should use the information from a range of sources (JSNA's, EHCPs etc) to identify this population with future housing needs.	Thank you for your comment. We agree that commissioners should plan for future needs in their area, using a range of sources of information. Planning for a range of future housing needs is covered in recommendation 1.5.1.
The Challenging Behaviour Foundation	Short	21	General	1.5.3-1.5.7	There is insufficient attention paid to the specific housing needs of this population- they are likely to require housing that is robust, may need soundproofing, extra space, specialist adaptations etc. This section is general housing issues for the learning disabled population – this guideline is for services for people with learning disabilities who display behaviour described as challenging who are likely to have specialist requirements	Thank you for your comment. We have revised recommendation 1.5.4 to say that when choosing where to live, take into account the person's preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation 1.4.1 on environmental factors in the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). This makes reference to the specific needs and requirements of people with learning disabilities and also behaviour that challenges. Recommendation 1.5.1 covers working with local housing providers to identify the specific housing needs of adults with a learning disability and behaviour that challenges and ensuing that a range of options are available that meet these needs and cater for different preferences and person-centre support needs. We did not find research evidence for this population about assistive technology to support independent living to be able to make stronger recommendations.
The Challenging Behaviour Foundation	Short	22	10	1.6	More emphasis is needed on: □ early intervention how children in out of area residential care who come home at weekends and holidays will be supported by community services	Thank you for your comment. After careful review, we think that these issues are covered sufficiently. The guideline as a whole places an emphasis on prevention and early intervention (see for example the 'aims and principles' section); and section 1.6 notes that interventions and support should be provided in line with the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). Support for children and young people in out of area residential placements who are visiting their families is covered in a number of recommendations, see for example, recommendations 1.6.9 and 1.6.11.
The Challenging Behaviour Foundation	Short	22	17	1.6.2	Specify what is meant by 'promote the upbringing' A child / young person should also have their educational needs taken into consideration when deciding which school is most appropriate. To reduce the need for out-of-area and residential school placements, appropriate in-area specialist provision needs to be developed as a priority. Also parents need to receive adequate support to support their children.	Thank you for your comment. The phrase 'promote the upbringing' is directly quoted from section 17 of the Children Act 1989, and the recommendation has been worded to reflect that this is part of a local authority's legal duty. The Guideline Committee agree that the educational needs of children and young people should be taken into consideration when identifying potential school placements. We think that this issue is covered sufficiently (and in recommendation 1.6.4). The importance of developing local capacity is covered in section 1.4 and the 'Aims and Principles' section. We have added a recommendation in section 1.6 Services for children and young people, to emphasise the importance of the availability of support for parents and carers (this is based on the recommendations in section 1.3, 'Early intervention and support for families and carers'.
The Challenging Behaviour Foundation	Short	22	4-9	1.5.8	Include ways of supporting families relationships here	Thank you for your comment. We have revised the recommendation to say: 'services should help people to make and maintain friends, relationships and social networks in their community.'
The Challenging Behaviour Foundation	Short	23	28	1.6.7	Specify how supporting links with family can be achieved. Link to "Keeping in Touch with Home" resource by CBF	Thank you for your comment. After careful consideration we think that these issues are covered sufficiently. For example, the recommendation emphasises that residential placements should be as close to home as possible, and that financial support for families to visit their child should be made available if necessary. Recommendation 1.6.9 also covers similar issues.

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The Challenging Behaviour Foundation	Short	23	4	1.6.4	How does this relate to Community CETRs?	Thank you for your comment. It is our understanding that CETRs are required only when there is a risk of inpatient admission.
The Challenging Behaviour Foundation	Short	24	20	1.6.11	Specify what is meant by 'explain'. Specify how Commissioners can challenge decisions they are not happy with.	Thank you for your comment. Recommendation 1.3.5 covers the things that the 'named worker' should advise families and carers about, this includes telling families how they can make a complaint.
The Challenging Behaviour Foundation	Short	24	22 30	1.7.1	Respite and short breaks for individuals whose behaviour challenges is essential- but often people are excluded because of their behaviour! Respite commissioned must take into account and meet - the environmental needs of the individuals using the respite, and the respite staff must be trained in PBS and behavioural approaches	Thank you for your comment. The Guideline Committee agree that respite and short breaks for individuals displaying challenging behaviour are essential and drafted this recommendation to ensure that these are made available on the basis of need. Section 1.9 focuses on staff skills and values, and recommends that staff providing direct support should be able to demonstrate competencies outlined in the Positive behaviour support competence framework.
The Challenging Behaviour Foundation	Short	25	17	1.8.1	And that the inpatient service can offer treatment that cannot be delivered in a community setting.	Thank you for your comment. This is covered by the statement 'their needs cannot be safely met in the community'.
The Challenging Behaviour Foundation	Short	25	2-12	1.7.2	Respite staff MUST understand and be trained in PBS approaches	Thank you for your comment. Section 1.9 focuses on staff skills and values, and recommends that staff providing direct support should be able to demonstrate competencies outlined in the Positive behaviour support competence framework.
The Challenging Behaviour Foundation	Short	25	23	1.8.2	With knowledge and experience of the specific situation the individual is in and the options available	Thank you for your comment. After careful consideration, we think that this is adequately covered in the recommendation. Section 1.9 also makes recommendations on staff skills and values.
The Challenging Behaviour Foundation	Short	26	1-4	1.8.3- 1.8.4	Strengthen the wording here as it appears too vague to be helpful. What information should commissioners specifically give families? Specify that the IMHA must have learning disability and challenging behaviour knowledge and expertise	Thank you for your comment. We have revised the recommendation to include reference to the specific information that should be given, including about rights and other possible options for treatment, care and support. The Guideline Committee agree that it is important that advocates have the skills and experience to work with people with learning disabilities and behaviour that challenges and their families. Recommendation 1.2.9 states that 'Local authorities should ensure that independent advocates working with children, young people and adults with a learning disability and behaviour that challenges have skills and experience in working with these groups, and in liaising with specialist learning disability services.'
The Challenging Behaviour Foundation	Short	26	17- 21	1.8.8	Strengthen the wording here as it appears too vague to be helpful. Specify who should offer which interventions. Surely early identification and interventions should occur prior to admission to an inpatient unit	Thank you for your comment. The Guideline Committee agree that it is important to emphasise prevention and early intervention before admission to an inpatient unit. The order of the recommendations places exploring all other options to inpatient admission first, the final recommendation 1.8.8. states that interventions should follow those in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for evidence- based interventions that specifically address their needs and the reason for their admission and who should deliver them. We have revised and strengthened other recommendations in placing a greater emphasis in prevention and early intervention.
The Challenging Behaviour Foundation	Short	26	5	1.8.5- 1.8.8	The first key point should be that the inpatient service can evidence that it can provide treatment that will deliver good outcomes (measurable against a baseline) for the individual, and has the skills and expertise to do so within agreed timescales! (i.e. they plan discharge on entry)	Thank you for your comment. The order of the recommendations places exploring all other options to inpatient admission first, the final recommendation 1.8.8. states that interventions should follow those in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11)or evidence- based interventions and that these interventions specifically address their needs and the reason for their

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						admission. The Guideline Committee agree that planning for discharge should happen straight away and made recommendation 1.8.9 that the lead commissioner should ensure that hospitals work together with community learning disability teams to develop a discharge plan as soon as the person is admitted.
The Challenging Behaviour Foundation	Short	27	1	1.8.10	Suggest remove 'Think about'.	Thank you for your comment. The strength of the wording in the recommendations reflects the strength of the evidence underpinning it. In this instance we did not have strong evidence to support one review framework over another, and the wording used allows for some flexibility in local level implementation.
The Challenging Behaviour Foundation	Short	27	15 & general	1.9	Suggest this section receives greater prominence. It is the workforce that makes up the services! We know that the Transforming Care programme has not addressed workforce and has been criticised by the NAO. Should there be agreed standards for those working with people with LD and how providers support and develop their workforce	Thank you for your comment. We have referenced the skills needed in staff training supervision and support in the clinical guidelines (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). National standards for staff development and formal qualifications are out of scope for this guidelines
The Challenging Behaviour Foundation	Short	28	11	1.9.6	Specify how this can be done.	Thank you for your comment. The Guideline Committee agreed that the level of detail in this recommendation was sufficient. This is on the basis that we did not find specific examples of what is effective or preferred by people who should be involved in the recruitment of staff. The guideline is relevant to an extremely diverse group of stakeholders and organisations and there is, therefore, a need for flexibility in local level implementation.
The Challenging Behaviour Foundation	Short	28	26		What about young people aged 12-18: how are they referred to? Check through document, as if 'children' only refers to 12 year olds and under there are places where there I reference to school, education, EHCPs etc. which apply to over 12s.	Thank you for your comment. We have checked all references to school, education and Educating, Health and Care Plans (EHCPs) in the guideline and made sure they refer to both children and young people.
The Challenging Behaviour Foundation	Short	33	19	Supporting family members, carers and staff	Agree this is an important research area, but it is linked to what support and services are actually available for their relative so this needs to be factored in too.	Thank you for your comment. We agree and This research question aims to answer the question on impact of what services are available
The Challenging Behaviour Foundation	Short	33	General	Research recommendations	We need more research evidence about investment in early intervention approaches for this group of children and adults and their families.	Thank you for your comment. The Guideline Committee agree and have included a research recommendation in this area. See the section on research recommendations in either the short guideline or full guideline.
The Challenging Behaviour Foundation	Short	6	9		Add Mental Health Act, DoLS, Human Rights Act,	Thank you for your comment. These have been added to the list.
The Challenging Behaviour Foundation	Short	7	10	Aims and principles	Add – exercise their Human Rights	Thank you for your comment. We have added the Human Rights Act 1998 to the list of relevant legal duties and guidance.
The Challenging Behaviour Foundation	Short	7	10-17	Aims and principles	Should service aims also include the need to seek the views and communicate effectively with people with learning disabilities and their families, to listen to and act on those views to ensure meaningful co-production of those services?	Thank you for your comment. This section sets out the aims and principles, and in the recommendations the ways in which to achieve them. Co-production is an important way of achieving the aims and principles. We have revised recommendation 1.1.7 to say that when planning and delivering services according to local need, services should be co-produced We have revised this recommendation to include information from co-production networks to identify gaps in service provision when developing services based on local needs. We have included a definition of co-production in the terms used section.
The Challenging	Short	7	10-17	Aims and principles	Specify that proactive preventative support that should be given to families so that they can support their loved ones proactively and avoid crises. Reference Ensuring Quality Services that the TC programme produced. Reference the CBF CDC Paving the Way report and that the Transforming Care programme	Thank you for your comment. Several recommendations have been revised to place greater emphasis on supporting families, and on prevention and early intervention to prevent crisis, specifically, the Aims and Principles of the guidelines, section 1.4 heading has been changed to emphasise that community services should be

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Behaviour Foundation					has set up a children and young people group in acknowledgement that this is an area that needs attention.	Services in the community – prevention, early intervention and response. Recommendation 1.4.11 has been revised to state that when reducing the level of support from more intensive services, lessons should be learned to inform future early intervention and prevention services and support crisis plans.
The Challenging Behaviour Foundation	Short	7	19	Aims and principles	Towards "real investment in"	Thank you for your comment. Recommendations in the Aims and Principles section aims to rebalance services by shifting focus towards families, prevention and early intervention would require shifting emphasis from inpatient and out-of-area towards investment in community based services. The resource implications of this rebalancing is discussed more in the linking evidence to recommendations economic considerations in the full version of the guideline.
The Challenging Behaviour Foundation	Short	8	10-13	1.1.2	Strengthen the wording here as it appears too vague to be helpful. Specify nature of the services required and what is meant by 'particularly complex needs'.	Thank you for your comment. The term 'complex needs' was retained to reflect the wide range of needs and conditions this encompasses. The phrase 'children, young people and adults' has been included to help make the recommendation clearer.
The Challenging Behaviour Foundation	Short	8	19-21	1.1.4	Strongly support the contingency fund. But this should be available for families to access as well as providers	Thank you for your comment and support for this recommendation. The wording of this recommendation reflects the evidence presented by the expert witness. The importance of providers working closely with families is a principle underpinning the whole guideline, and referenced explicitly in recommendations within section 1.2.
The Challenging Behaviour Foundation	Short	8	3-9	1.1.1	Strongly support this recommendation	Thank you for your comment, and for your support for the guideline.
The Challenging Behaviour Foundation	Short	8	3-9	1.1.1	Specify the role, responsibilities and requisite experience of the specialist commissioner	Thank you for your comment. Recommendations 1.1.1 and 1.1.2 outline the role and experience of the lead commissioner.
The Challenging Behaviour Foundation	Short	8 - 9	22 (p.8) -16 (p9)	1.1.5	Planning and delivery of community services also requires the input of the 'people' and their families. Early identification of need in childhood is also crucial, as is the development of early intervention services.	Thank you for your comment. The Guideline Committee agreed this was important and section 1.3 has been updated accordingly. It was the intention that the recommendations in this section address early intervention and this has been made clearer. This has also been emphasised in an explanatory statement on p7-8 of the guideline.
The Challenging Behaviour Foundation	Short	9	16	1.1.5	Specify what is meant by 'integrated'	Thank you for your comment. We have revised this recommendation to read: 'integrates health, social care and other relevant services.'
The Challenging Behaviour Foundation	Short	9	18	1.1.6	'Single care pathway' There is a need to ensure all relevant parties – especially families – are aware of and understand this pathway	Thank you for your comment. We agree that all relevant parties, especially families should be aware of and understand the pathway. We have referenced the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) section on organising care and this includes the recommendation that pathways should be: "negotiable, workable and understandable for people with a learning disability and behaviour that challenges, their family members or carers, and staff"
The Challenging Behaviour Foundation	Short	9	27-31	1.1.7	Families also need to be actively involved in 'managing risk' in the development and delivery of their loved ones care – specify how this could be done	Thank you for your comment. We have revised recommendation 1.4.8 to include assessments of both need and risk. Specific risk assessments are referenced in section 1.5.7 on risk assessment in the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11). We have referenced the clinical guideline where appropriate.
The Challenging Behaviour Foundation	Short	general		general	These guidelines aim to reduce inpatient admissions in line with the Transforming Care Programme (TCP), however there is no mention of autism. Given that autism is a social communication impairment that affects (to a great or lesser extent but in ALL cases) understanding and using language, flexibility in thinking, social interaction and sensory processing which can mean a person	Thank you for your comment. The scope of the guidelines includes people with autism and who also have a learning disability. After further consideration. The Guideline Committee agreed that this needed greater clarification and have revised the background section to make this clearer. However, the population is in line with the clinical guideline (Challenging behaviour and learning disabilities: prevention

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					with autism may display behaviour that challenges as a result of their neurodisability, irrespective of their IQ. For people with autism who display behaviour that challenges, there is therefore an equal need for functional behaviour analysis and positive behaviour support. Suggest that this guidance should refer to people who learning difficulties, autism or both – as recognised by, and in line with, the TCP.	and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) that accompanies this service guideline and includes: • lower intellectual ability (usually an IQ of less than 70) significant impairment of social or adaptive functioning • onset in childhood. NICE has also produced a guideline specifically for adults with autism spectrum disorders. (Autism spectrum disorder in adults: diagnosis and management. Clinical guideline CG142).
The Challenging Behaviour Foundation	Short	General	general		There is a need to ensure that all support and services for this group of individuals focusses on early intervention and prevention, and that the support and services are co-ordinated and focussed on positive outcomes for the individuals. This will include prioritising early and ongoing support for families. We would like to see a greater emphasis on support and services for families in the guideline, as valued and long term partners.	Thank you for your comment. Recommendations 1.3.1 to 1.3.5 refer to early intervention and support for families, including specialist services working in partnership with families to support them in their caring role.
The Challenging Behaviour Foundation	Short	general	general		The CBF strongly supports the recommendation that each area has a single lead commissioner responsible for commissioning health social care and education for children, young people and adults with a learning disability, and that this commissioner has in-depth knowledge and expertise in working with people with a learning disability and behavior that challenges. For children, this commissioner should inform the SEND joint commissioning process.	Thank you for your comment and your support for the guideline. The Guideline Committee considered this feedback and have amended the recommendation to state that, whilst the commissioning function for this population should be overseen by one individual, this function could comprise broader joined-up commissioning arrangements to ensure a range of skills and sufficient capacity.
The Challenging Behaviour Foundation	Short	general	general		The use of the term "experts by experience" must be clarified. It means different things to different people (e.g. CQC, providers, NHSE). Where ExEs are involved there must be a clear commitment to their ongoing support and training	Thank you for your comment. We agree the term 'experts by experience' needs clarification as it can mean different things to different people. For terms that have a specific meaning in the context of this guideline, we have explained what we mean by them in the list of terms used in this guideline. Experts by experience is included in the list.
The Family Carer Support Service	Short	15		1.3	1.3 All staff should have a basic understanding of carers rights to support under the Care Act 2014 and encourage family carers to have a carers assessment. This is especially relevant when an individual's support is funded by health as their carer may not be known to the local authority.	Thank you for your comment. Recommendation 1.3.5 includes advising family members about their right to, and explaining how to get 'carer's breaks services' and information about 'community resources, including voluntary organisations, networks and support groups'.
The Family Carer Support Service	Short	20		1.5	1.5 We welcome the emphasis on people having a range of housing options and the option of living close to family. We know that there is a national shortage of housing which is compounded by the refusal of private landlords to accept tenants in receipt of welfare benefits. One Family carer wrote "In local areas especially London, there is reducing housing capacity and what is there is unaffordable. Private landlords are reluctant to take benefit tenants and with Universal credit the gap between benefit and actual rent cost is hitting more claimants and this is likely to increase, as is the size of the gap between benefit and rent cost. Voluntary Sector organisations do not have funding to embark on capital housing projects to fill the gap in supported living or tenancies suitable for people with extra needs or challenging behaviour" In reality many people labelled as having challenging behaviour are not given a choice of accommodation that can meet their needs. Often people end up living miles away from their family because local provision is inadequate. As well the considerable emotional strain this puts on the individual and their family, it can also be a financial burden that is often overlooked by commissioners.	Thank you for your comment. The Guideline Committee agreed on the importance of accommodation as a determinant of health and wellbeing. While there was not strong evidence to support recommendation of one type of housing over another, or the maximum number of residents to maximise choice, control and wellbeing. The Guideline Committee felt strongly that accommodation should be personalised to the needs and preferences of adults with learning disabilities and behaviour that challenges and this would likely be small, home-like environments with people having a choice over who they live with.
The Family Carer	Short	25		1.8 & 1.8.3	1.8 & 1.8.3 When a person is admitted to a hospital, that person and their family carers should be given practical information about the hospital, contact details and names of key staff members. Families should be given information	Thank you for your comment. After careful review, we think that these issues are adequately covered in recommendations 1.8.3, 1.8.4, 1.8.6, and 1.8.7.

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Support Service					about what to expect while their relative is in hospital, including the hospital's policy on use of restraint (physical and chemical). Family carers should be involved in discussions about how staff will try to support their relative when they display "challenging behaviour" and how and when they will be informed of any incident. Families should be given information about the complaints procedure. When a person with a learning disability is admitted to a hospital, this should be flagged electronically on their patient records; if reasonable adjustments are required, these should be identified and recorded. Where available, learning disability liaison nurses should be made aware of the admission and family carers should be offered support from the liaison nurse. Family carers should have access to support around changes to benefits while their relative is in hospital and be offered an opportunity to link in with other families for peer support.	
The Family Carer Support Service	Short	26		1.8.9	1.8.9 Discharge planning should also consider how the needs of family carers may increase when their relative is discharged from hospital, whether or not their relative lives with them. Family carers should be reminded of their right to a carer's assessment or a review of their carers assessment during discharge planning meetings.	Thank you for your comment. The recommendation that follows 1.8.9 on discharge planning, 1.8.10, is about the review of the discharge planning, and this includes the person and their families and carers in the review process. The recommendation also suggest that the Care Programme approach could be used, which includes the care coordinator arranging a carers' assessment if this is wanted.
The Family Carer Support Service	Short	27		1.9	1.9 Family carers should be treated with dignity and respect, including when they raise concerns. They should not to be referred to in derogatory terms such as difficult or over protective.	Thank you for your comment. We have referenced the staff qualities that were important to the Guideline Committee. These reflect the qualities of dignity and respect
The Family Service	Short	8		1.1.1 and	**1.1**	Thank you for your comment, and for your support for the guideline.
The Family Carer Support Service	Short	8		1.1.1 and 1.1.12	**1.1** We welcome the introduction of p1.1.1 "single lead commissioner who would be responsible for commissioning health, social care and education services for children, young people and adults with a learning disability, including for those whose behaviour is described as challenging" A lead commissioner would be able to assess the needs of people across the whole range, rather than the current situation of separate commissioners in a piecemeal fashion. Such a holistic approach should allow priority needs to be identified across disciplines in order to deliver the best outcomes for people with learning disabilities and behaviour that challenges. Through our support work we know that there is a national shortage of Speech and Language Therapy provision. One family carer wrote to say *"regarding speech and language therapy the current situation is chronically in deficit since my daughter - who is a non-verbal AAC user and will need lifelong provision to enable her communication systems to be maintained and provided and enhanced - does not fit the CCG criteria which are very narrow; you have to actually have mental health problems or challenging behaviour to qualify. She will have to suffer deterioration and distress (and possibly damage through an accident) before she qualifies for SaLT provision"* Even when SaLT provision is specified in sections B and F of a person's Education Health and Care plan, we have supported family carers who experience major delays in getting this provision. "Challenging behaviour" is far more likely to occur when a person is frustrated that they are not being heard/ understood which is why we recommend that that provisions for Speech and Language Therapy is a top priority for commissioners.	

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					We welcome the recommendation of "commissioners employing experts by experience in their commissioning teams in order to inform decision-making and quality assurances of services" 1.1.12. We recommend that is made up of people with learning disabilities and family carers. To avoid tokenism, people with learning disability should be supported to meaningfully engage in commissioning.	
The Family Carer Support Service	Short	General	general		Hft's Family Carer Support Service response: Learning disabilities and behaviour that challenges: service design and delivery. NICE consultation. Hft is a national charity supporting people with learning disabilities and their families. We are committed to supporting people with learning disabilities to live the life they choose. Hft's Family Carer Support Service (FCSS) provides information and support to family carers supporting a relative or friend with a learning disability anywhere in England. We do this through: • ongoing support given by telephone, email and letters • participative workshop courses so groups of relatives acquire skills and knowledge they need to understand and engage effectively in processes affecting their relative and themselves • the production of resources specifically tailored to the support roles family carers play throughout phases and aspects of their relative's life • working in partnership with others to help raise the profile of family carers, their needs and contributions, in research, health and social care, as well as mainstream initiatives. This response is based on our knowledge of family carer experiences through our support work and responses from family carers who are members of our service. Overall the feedback to the consultation is welcomed by family carers and our organisation.	Thank you for your comment.
The Family Carer Support Service	Short	**General**	general		Over medication, of people with learning disabilities is a major concern for family carers, and it particularly affects people labelled as having "challenging behaviour" We would welcome updated recommendation on use of antipsychotic in this consultation. Family carers frequently contact us for advice when their relative is prescribed antipsychotic medication, which they often attribute to rapid weight gain and depression in their relative. When anti psychotics are prescribed as a P.R.N families are often extremely worried about support staff lacking appropriate medical training to know when to administer. Although current guidance states that P.R.N. should only be prescribed for as short a time as possible, this is not always the case. We have supported too many families who have been dismissed or treated appalling by psychiatrists, when they have raised concerns about use of antipsychotics for their relative.	Thank you for your comment. We agree it is helpful to highlight the importance of regularly reviewing medication. This is covered in recommendation 1.2.22. We reference the recommendations set out in the NICE guidelines: (Managing medicines for adults receiving social care in the community. NICE guideline NG67) for adults receiving social care in the community and the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) for people with a learning disability and behaviour that challenges using inpatient services.
University Hospital	Short	10	19	1.1.10	Question 2 – There may be a cost implication if carers/relatives are included in the multi-agency group. However, involving experts by experience (especially	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist.

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Birmingham NHS Foundation Trust					people with learning disabilities) can help people with learning disabilities overcome challenges	However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. It considered the recommendations to be aspirational but achievable.
University Hospital Birmingham NHS Foundation Trust	Short	10	23	1.1.11	Question 2 – There may be a cost implication if more information about services is made available to people with learning disabilities and their families/carers to avoid crisis	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable.
University Hospital Birmingham NHS Foundation Trust	Short	10	6	1.1.8	Question 3 – Satisfaction ratings of people with learning disabilities and their families/carers who have used the services would help users overcome challenges	Thank you for your comment. To take into account stakeholder consultation feedback, this recommendation has been updated to include reference to quality of life ratings, as suggested. It also now references quality checks by user organisations and quality review visits from community learning disability teams.
University Hospital Birmingham NHS Foundation Trust	Short	11	14	1.2.3	Question 2 – Housing related support which helps people with learning disabilities to live more independently can be challenging to implement and may have a cost implication to fund more housing and extra support may be needed to maximise that independence	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of their recommendations and were aware of the widespread resource constraints that exist. However, the Committee thought it was important to recommend and highlight best practice, based on the research evidence. They consider the recommendations to be aspirational but achievable. The Resource Impact report considered the impact of the recommendations and their potential costs and savings. The additional support recommended to enable people to be supported to live where and how they wish was considered to be in line with the Transforming Care programme which aims to shift emphasis from inpatient care in mental health hospitals, towards care provided by general and specialist services in the community.
University Hospital Birmingham NHS Foundation Trust	Short	12	10	1.2.7	Question 3 – There is a need to implement joined up care with GP's and acute hospitals for sharing information about people with learning disabilities communication needs	Thank you for your comment. We have revised this recommendation to include reference to the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of people, carers and families with a disability, impairment or sensory loss using health and social care services.
University Hospital Birmingham NHS Foundation Trust	Short	12	25	1.2.10	Question 2 – There will be a cost implication if more named workers in the community LD teams are to be employed. This is a service which is necessary to ensure people with learning disabilities have the right support from specialist services	Thank you for your comment. The Guideline Committee was in agreement that assigning a single practitioner to the role of 'named worker' would help to improve services for people with a learning disability. The wording of this recommendation has been amended to clarify that this role would be assigned to an existing member of the person's support team, rather than requiring employment of new staff.
University Hospital Birmingham NHS Foundation Trust	Short	12	7	1.2.6	Question 3 – Our Trust implemented an electronic system whereby patients communication needs are recorded and shared with others	Thank you for your response. We will pass this information to our local practice collection team. More information on local practice can be found here (https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies)
University Hospital	Short	22	10		Question 1 - Need to ensure that people with learning disabilities and services are joined up when children are transitioning into adult services.	Thank you for your comment. The guideline recommends a lead commissioner across children's and adults services (recommendation 1.1.1) to support good transitions.

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Birmingham NHS Foundation Trust					Our Trust has good links with local children's hospital which helps develop plans for transition	
University Hospital Birmingham NHS Foundation Trust	Short	27	15		Question 1 – Staff training for knowledge and skills has a big impact on practice and can be a challenge to implement in large organisations	Thank you for your comment. Section 1.9 of the guideline outlines staff skills and values.
Westminster City Council	Short	19	10	1.9.4	Intensive support services that can respond to a crisis within an hour, this clearly has significant implications for service configurations and funding, but is there an evidence base and again raises concerns about the focus on crisis rather than prevention.	Thank you for your comment. We hope that the guideline will inform commissioning and workforce planning in local areas to ensure capacity to deliver the recommended services. We have revised the recommendation 1.4.10 to read that there should be a local, personalised response to children, young people and adults who need intensive support during a crisis. This should include a telephone response in one hour, by staff with specialist skills and knowledge about the needs of people with learning disability disabilities and behaviour that challenges, and specialist skills in mental health problems, and to provide a face-to-face response within 4 hours if that is what is needed. The resource impact team did consider that the provision of intensive support during a crisis would likely incur costs to implement. They also said that implementing the guideline may also results in the following benefits and savings: lower rates of placement breakdown due to effective respire care and suitable housing. The unit cost per case of £31, 296 for a crisis resolution team for adults is taken from the unit costs of health and social care 2017. Lead commissioners will need to have 24/7 multi-disciplinary crisis support, and services should be developing in this way to meet the requirements of the Transforming Care agenda. The Guideline Ccommittee's view was also that investment in the service recommended here would lead to savings elsewhere in the system.
Westminster City Council	Short	27	15	1.9.1	It is considered if it would be helpful to be specific about types of training e.g. risk assessment (including something about positive risk taking), functional analysis (something about placing emphasis on understanding a behaviour), understanding issues related to Mental Health, understanding autism, working with complex needs, etc.	Thank you for your comment. The Guideline Committee agree that it is important for staff to be able to understand behaviour and we have referenced the clinical guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) general principles of care.
Westminster City Council	Short	27	23	1.9.1	Values - Again, it is considered if it would be helpful to say more here. For example, inclusion, choice, appreciating the impact of someone's context on their behaviour, also something about "not making the person the problem", something about organisations being open / transparent and willing to work with specialists in community team, willingness to evaluate their practice against best practice frameworks etc.	Thank you for your comment. We have referenced the clinical guideline that accompanies this service guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline NG11) in this recommendation. The clinical guideline includes under general principles of care: • ensure that the focus is on improving the person's support and increasing their skills rather than changing the person, • 1.1.3 Understanding learning disabilities and behaviour that challenges • 1.1.6 Staff training, supervision and support.
Westminster City Council	Short	General		General	On the whole this appears to be a helpful document and should hopefully be a powerful document for arguing the further development of services for this client group. The idea of pooled budgets and a single commissioner is certainly appealing.	Thank you for your comment and support for this guideline.
Westminster City Council	Short	General		General	It generally appears that the document is focused on how services respond when someone has challenging behaviour or is in crisis, it would be good to consider in line with the PBS model that there is more focus on what services can to, as much as possible, avoid people developing challenging behaviour in	Thank you for your comment. Several recommendations have been revised to place greater emphasis on supporting families, and on prevention and early intervention to prevent crisis, specifically, the Aims and Principles of the guidelines. Section 1.4 heading has been changed to emphasise that community services should be Services in the community – prevention, early intervention and response.

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					the first place, i.e. proactive interventions around training, support and service development.	Recommendation 1.4.11 has been revised to state that when reducing the level of support from more intensive services, lessons should be learned to inform future early intervention and prevention services and support crisis plans.