NATIONAL INSTITUTE FOR HEALTH AND   
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Service model for people with a learning disability and behaviour that challenges.

Date of quality standards advisory committee post-consultation meeting:   
24th April 2019.

1. Introduction

The draft quality standard for Service model for people with a learning disability and behaviour that challenges was made available on the NICE website for a 4-week public consultation period between 18th February and 18th March 2019. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 28 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

1. Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

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

4. Do you have any comments on combining this quality standard with the existing quality standard on learning disabilities: challenging behaviour, which covers care and support for adults, young people and children with a learning disability and behaviour that challenges?

5. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the [NICE local practice collection](https://www.nice.org.uk/about/what-we-do/into-practice/local-practice-case-studies/submit-a-case-study-example) on the NICE website. Examples of using NICE quality standards can also be submitted.

1. General comments

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

* The draft quality standard was well received.
* There were queries about the definition of behaviour that challenges and inclusion or exclusion of specific groups of people.
* Stakeholders were concerned that the definition used in the quality standard is old and not specific enough.
* There was concern about the use of the word ‘people’ rather than identifying that the standard covers children and young people as well as adults.
* Clarity regarding the definition of ‘carer’ – is this paid or unpaid, within the family or outside?
* The link between behaviour that challenges and communication should be highlighted as challenging behaviour is often used as a mode of communication.
* The need for inclusion of other support services in implementation was highlighted:
  + The use of advocacy services should be included in equality and diversity considerations.
  + The inclusion of speech and language therapists in the equality and diversity considerations was well received but stakeholders felt that a change to the language was required to highlight that these practitioners would also work with family members.
  + Royal College of Speech and Language Therapists 5 Good Communications standard should be referenced.
* Concerns were raised about ensuring smooth transfer of information between multiple agencies.
* Important to mention ‘whole life services’, as patients will require support for their whole life although the degree of support may vary over time. This includes statutory services as well as direct care providers and support services.
* There were suggestions that the type of support should be defined to include techniques such as positive behavioural support and trauma informed care.
* Training and ability / knowledge of staff responsible for services was felt to be lacking in some instances when referring to learning disability services outside of a crisis context.
  + Communication training provision should be included as up to 80% of people with learning difficulties have communication problems.

### Consultation comments on data collection

* Concerns were highlighted about who would be responsible for collecting and analysing data and who would fund this.
* Concerns about patient reported outcomes:
  + Up to 80% of people with a learning disability have communication problems so additional support for self-reported satisfaction will be required.
  + Achievement of person-centred goals may be a better measurement.
* Query over use of inpatient admission numbers as an outcome.

### Consultation comments on resource impact

* There were many concerns about limited funding in this area including shortage on resources and workforce.
* There was acknowledgement of current improvement campaigns and projects.

### Consultation question 4

Do you have any comments on combining this quality standard with the existing quality standard on [learning disabilities: challenging behaviour](https://www.nice.org.uk/guidance/qs101), which covers care and support for adults, young people and children with a learning disability and behaviour that challenges?

* Stakeholders agreed that these quality standards should be combined.

1. Summary of consultation feedback by draft statement
   1. Draft statement 1

Local authorities and clinical commissioning groups jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability.

### Consultation comments

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

* Stakeholders welcomed the shared approach to managing risk. They queried the experience and knowledge required for the position.
  + It may be difficult to find someone with experiences in children and adult services.
* The commissioner should consult with service users in planning and delivery of services.
* Stakeholders queried the position of the joint lead commissioner:
  + A commissioning board may work better and prevent working in isolation.
  + The level of position in both organisations should be equivalent.
  + Pooled budgets should be evidenced.
* Outcome measure a):
  + extend to reporting of satisfaction with services from families and carers.
  + Difficulties with self-reporting in this group of people should be considered.
  + May not accurately reflect effectiveness of the lead commissioner role
* Queries about the appropriateness of outcome b):
  + Hospital admission may be unavoidable and may be the safest place for some people.
  + Could be broken down for example delayed discharge and length of stay.
* Increased funding for advocacy services and joint funding for the post of lead commissioner needed.
  1. Draft statement 2

People with a learning disability and behaviour that challenges have a named lead practitioner.

### Consultation comments

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

* There was agreement that this is a key area of improvement. Lead practitioners have been shown to be beneficial to families with disabled children but are not consistently commissioned.
* Questions about where this role would sit and what qualifications, knowledge and experience would be required:
  + Would need all agencies signed up to acknowledge the influence on multiple systems to ensure this role is different from existing care coordinator roles.
  + The need for the practitioner to understand the persons view and take an active role in getting to know them and their families.
  + Who will appoint the lead practitioner? – this should be the lead commissioner’s role.
  + Acknowledgement that the lead practitioner may change over time according to their skills and knowledge and requirements of the person.
  + Clarification that the role may not be a health practitioner only but may be a social worker, occupational therapist or other service provider.
  + There may be resource implications – what is the case load for the lead practitioner?
* There is a role for speech and language therapists as well as family members to allow for effective communication with the person.
* Clarification of who would benefit from a lead practitioner. This statement assumes that all people are engaged with statutory services.
* There may be people with a learning disability and behaviour that challenges who are not on a current caseload but would require a named lead practitioner. This information may not be easily obtainable.
* There is no reference to carers outside of the family.
* Family and carers should be included in data collection for satisfaction of services.
* GP practices may not keep coded data about lead practitioners so may be difficult to measure.
  1. Draft statement 3

Families and carers of people with a learning disability and behaviour that challenges are involved by services in developing the person’s care and support plan, which includes how to prevent or respond to a crisis.

### Consultation comments

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

* The statement reflects a key area for quality improvement.
  + Person centred care is central to the Children and families Act.
  + Co-production remains an aspiration rather than a reality in most areas.
* Expand statement to include the person with learning disability and behaviour that challenges.
  + Should include reasonable adjustments in line with the Mental Capacity Act.
* The lead commissioner and lead practitioner will need to clearly outline the responsibilities and accountability for family and carer support.
* Standardised training is needed for family and service providers.
* Widen audience descriptors to include education providers.
* It would be helpful to define carer – unpaid or paid support staff?
* There were queries about the definition of the care and support plan.
* Outcome measure:
  + May not be appropriate as the decision could still be made to live in a supported environment.
  + Some people have no family engagement and this data should be collected.
  + Measure proportion of people who live in their own home or with family with agreed care plan in place.
  + Family reporting of satisfaction with quality of the plan and their involvement.
  + Co-production should be evidenced in service area development. Case notes should record meetings involving families and carers.
  + Family and carer involvement may not always be clear for audit purposes. Multiple agencies are likely to be involved who have their own care plans so may be difficult to measure.
  + Could audit availability of appropriate respite services that meet the need of the local population.
  + Data would only be available for those on current caseload. Consideration should be given to those not on current caseload who have a support plan in place or require one.
  + Additional outcome on timely access to services for families and carers.
* Funding and resource issues were a concern by stakeholders.
  + There is no mention of cost for collection of meaningful data.
  + May need investment in out of hours services for prevention of crisis and contingency planning.
  + Care hours are currently limited to direct support or training and investment in proactive and meaningful engagement is often not supported.
  + Families and people with a learning disability will need support from advocacy family support organisations independent of services. This may have cost implications.
  1. Draft statement 4

People with a learning disability and behaviour that challenges can have specialist behavioural support in the community.

### Consultation comments

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

* The statement was identified as a key area of improvement.
  + Waiting times are long for mental health services.
  + There is a lack of articulated and resourced expectations from partner agencies
* Stakeholders queried the definition and content in the support specified in the statement:
  + It should include early access for assessment and/or intervention.
  + Should focus on local services.
  + ‘Timely’ support.
* It was felt that a range of other health professionals should be included in the provision of specialist assessments
  + Clarity is required on what constitutes a profession trained in helping people with a learning disability and others to understand and change behaviour that challenges, and how this will be measured.
* Will need clarity regarding responsibilities for all agencies to ensure 7-day services.
* Link to the lead practitioner to ensure care is coordinated.
* Stakeholders felt that a wide range of behavioural support techniques and thus training should be considered and defined.
  + Training of families and service providers.
  + Suggest audit of staff work appraisals and evidence of in vivo quality checks to supplement training completion data.
  + How will training be benchmarked to ensure quality service?
* It was suggested that some of the language used throughout this statement should better reflect the person with a learning disability and behaviour that challenges and their requirements.
* There is no reference to other carers beyond the family.
* Stakeholders again identified this as an area the requires investment in funding and in resources.
  + Funding for the support required will be needed from all services involved.
  + Increased capacity of community learning disabilities team will be needed.
  + Services could build on current provision including those services that are not called behavioural support.
* Outcome does not reflect the statement:
  + Circumstances could still arise where people require hospital admission, or to be looked after somewhere other than their own home.
  + Quality of life measures may be more appropriate.
  + Consider inclusion of family reported satisfaction.
  + Outcome should be delivery of staff training.
  + Data would only be available on current open caseload. Some people may be accessing this type of support still relevant from previous contact with a professional in the community, but this data may be difficult to collate.
  1. Draft statement 5

Adults with a learning disability and behaviour that challenges are supported to live where and how they want.

### Consultation comments

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

* There was agreement that this reflects a key area for quality improvement.
* Barriers to implementation were identified:
  + This area is impacted by social care budget and range of specialist providers skilled to support people with LD and behaviour that challenges.
  + The transforming care agenda encourages people to live in geographical area based on commissioning rather than a choice of where people may want to live.
  + Additional funding would be needed for transition.
  + Joined up working of adult and children’s services are limited in many areas.
* Stakeholders suggested changes to the wording of the statement specifically using the language “meets their needs”:
  + Statement is open to interpretation.
  + Include “subject to agreement” to avoid placement with risk of abuse or illegal placement.
  + Exploration of the compatibility of people with others in their housing in terms of choosing where they want to live should be considered.
  + People should have the same choices as anyone else in their local community.
  + Amend to “people are supported to have their views taken into account”. Measurement of the availability of options and presence of discussion about the options may not accurately reflect if people have felt heard or ended up living where they would wish.
  + Add that the focus should be on smaller community-based placements as the preferred alternative. Congregate settings and those that are separate from the communities that people live can limit quality of life.
  + Include reference to be an active member of the community or include the development of relationships.
  + Could be expanded to include other needs such as employment, financial independence.
  + There is nothing about safeguarding against isolation, exploitation or discrimination.
* Stakeholders felt that other services and practitioners could play a role in provision of this statement.
* Outcome:
  + Does not reflect the statement.
  + Should reflect choices of where to live and how to live within the realistic options available and address responsibilities as tenants and citizens.
  + Need a more validated easy read research measure on quality of life.
  + Fails to take into account the impact of Registering the Right Support.
  + Could measure that commissioners have an accommodation plan that maps potential housing needs over a long period and includes a range of options.
  + Evidence of housing specifications that have been developed in partnership with the individual and their families.
  + Define equipment and adaptations required for housing needs for which assessment may be required.

1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* Early intervention and prevention services.
* Annual learning disability reviews / health checks.
* Positive behavioural support to be available 24/7.
* Transition from children’s to adult services

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

| **ID** | **Stakeholder** | **Statement number** | **Comments[[1]](#footnote-1)** |
| --- | --- | --- | --- |
| 1. 1 | 2gether NHS Foundation Trust | General comment | We noted very little mention of Positive Behavioural Support (PBS) throughout the document, which was surprising given the evidence base for this approach. |
| 1. 2 | British Enhancement Centre (BEC) | General comment | The fundamental issue is that young people of all abilities have a right to contribute in anyway they can and it is the responsibility of a progressive society that this contribution is welcomed and respected. Government needs to recognise that in order to do this, society needs to invest in the infrastructure that meaningfully allows for this to happen. We at BEC feel that this is a fundamental right and the price of not doing this is too high |
| 1. 3 | Future Directions CIC | General comment | General Comment - does the term challenging behaviour (CB) cover people who offend or are at risk of offending? |
| 1. 4 | Home From Home Care Limited | General comment | NICE quality standards, if they are to be credible must take account of the realities about workforce and funding in children’s and adults learning disability services. There is a chronic shortage in the specialist work force, funding challenges for the NHS and local authorities and a set of proposed quality standards that take no account of this. Additionally, recommendations are made about surveys to be conducted as evidence for progress but with no reference to who will fund the data collection let alone analyse and interpret the data. Recommendations and proposals from NICE now need an economic impact assessment to sit alongside your equality impact assessment. If you cannot say how much it will cost it has no relevance. |
| 1. 5 | Mencap | General comment | It would be helpful to use definition of behaviour that challenges from The Royal College of Psychiatrists' 2007 report ‘Challenging behaviour: a unified approach defined 'challenging behaviour' - 'Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'  It is important to refer to quality of life. The Unified Approach is also used in other guidance so would make sense to use it here.  When using the term ‘services’, it would be helpful to define what this means/ what type of services we are talking about. |
| 1. 8 | NHS England | General comment | * Care consistent with this quality standard is fairly wide spread, we have commissioning team for this group of population and general practitioners are contributing towards general care needs of this population. * Biggest barriers in the adoption of this quality standard is likely to be in implementation/adoption of these quality standards. It is likely to be related to boundaries observed by various services who need to get together in order to implement coherent, effective care plans. * Support for families and carers and services in the community might require additional funding and workforce to deliver. It is mainly because of limited resources and available practitioners who are able to meet the demand. Paperwork and smooth transfer of information between multiple agencies is also likely to have impact on the effective delivery against recommended quality standards. |
|  | Pennine Care NHS Foundation Trust | General comment | It is positive that the document includes children. |
| 1. 11 | Royal College of General Practitioners | General comment | The RCGP is currently working on improving the quality of psychotropic prescribing for patients with learning disabilities and or autism.  <https://www.rcgp.org.uk/clinical-and-research/about/clinical-news/2019/january/psychotropic-prescribing-for-patients-with-learning-disabilities-and-autism.aspx> |
| 1. 13 | Royal College of General Practitioners | General comment | The quality standard does not refer to annual learning disability reviews/health checks which may assist to detect and manage health conditions early, review current treatments are appropriate, to coordinate support for people with learning disabilities and to help build continuity of care.  <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>  <https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/learning-disabilities.aspx> |
| 1. 16 | Royal College of General Practitioners | General comment | There needs to be positive behavioural support available 24/7 to help keep service users in their own homes and to avoid hospitalisation. There is often a lack of accommodation locally, particularly in large cities, so people with learning disabilities with behaviours that challenge are transported to other areas where there may be provision and care costs may be lower. The number of children with a learning disability or autism detained in institutions has more than doubled since 2015.  <https://files.digital.nhs.uk/A9/32CBC9/ldsm-Apr-18-main-report.pdf> |
| 1. 18 | Royal College of Nursing | General comment | No comments. |
| 1. 19 | Royal College of Psychiatrists | General comment | RCPsych has provided input before into previous consultations which have been referred to in this consultation exercise, and pleased to see that many of them have been taken on board. |
| 1. 20 | Royal College of Speech and Language Therapists | General comment | Many of the standards may be challenging to accurately measure if considerable support is not put in place. For example: ‘*Self-reported level of satisfaction with services among people with a learning disability’* would involve complex conversations with people with learning disabilities and will require high functioning language ability. It is therefore essential that specialist support such as a speech and language therapist is available.  We also recommend further thought is given to how this standard would be measured and effectively achieved with full involvement from the people with learning disabilities. |
| 1. 22 | Royal College of Speech and Language Therapists | General comment | We welcome the acknowledgement of the need for speech and language therapists in the equality and diversity considerations. However we recommend that this is strengthened by a slight reword to say:  “This may include involving speech and language therapists or AND working with family members on finding solutions to allow for effective communication.” |
| 1. 23 | Royal College of Speech and Language Therapists | General comment | It feels a lost opportunity not to be making the links between behaviour and communication. The evidence shows that people may present with challenging behaviour which is often used as a mode of communication. We would recommend that this link is highlighted in the introduction. |
| 1. 24 | Surrey & Borders Partnership NHS Foundation Trust | General comment | Transition appears not to be specifically highlighted in the guidance. There are multiple examples of people moving from child to adult services, or from one locality to another and poor/non-existent handover from previous services. The leads to sudden “crisis” in terms of escalation in behaviour or lack of provider understanding/tolerance of behaviours. |
| 1. 25 | The British Psychological Society | General comment | The Quality Standard needs to more specifically consider attachment and emotional issues. It is possible to measure observable behaviour linked to emotional developmental stages and these need to be acknowledged when looking into the meaning of behaviour. The standard should demonstrate an understanding of the meaning of behaviour as related to these factors, and the need to consider the role of attachment and the value of implementing a trauma-informed care approach. There needs to be more consideration of these factors throughout the Standard.  References:  DCP FPID (2017) Incorporating Attachment Theory into Practice: Clinical Practice Guideline for Clinical Psychologists working with People who have Intellectual Disabilities  Frankish, P. (2013) Facing Emotional Pain—a Model for Working With People With Intellectual Disabilities and Trauma. Attachment: New Directions in Psychotherapy and Related Psychoanalysis, 7, 276-282.  Frankish, P. (2016). Evaluating the Impact of Providing Training for Direct Care Staff in how to Provide an Emotionally Nurturing Environment for People with Intellectual Disability and Complex Needs. Journal of Intellectual Disability – Diagnosis and Treatment, 4, 41 – 43. |
| 1. 27 | The British Psychological Society | General comment | We acknowledge that this Quality Standard has been developed with well-supported involvement from and co-production with Experts by Experience, which is commended. |
| 1. 28 | The British Psychological Society | General comment | We have concerns about the definition of ‘behaviour that challenges’. The definition provided is now very old (Emerson, 1995), and we are concerned that it is not specific enough. It takes no account of the meaning of behaviour and does not adequately consider the role of emotional issues and attachment. This needs to be more fully explored in the quality standard document as a whole. For example, the definition should include reference to “regression to infantile behaviours” when distressed.  Furthermore, we have concerns that including behaviours that may place the person at risk of vulnerability are not specifically included. Examples include being sexually disinhibited and taking their clothes off in public or using sexualised language when they do not have capacity to consent; impulsivity when walking outside, etc.  The definition is so open to include a wide range of people with learning disabilities known to services. However there is a risk that the inclusion criteria is too wide and is not meaningful in focusing on those who particularly require a positive behaviour support framework. These behaviours include those whose ‘behaviour’ is secondary to psychological distress or ‘mental illness’, which might be better managed under an alternative pathway.  There is a need for further clarification that many people who present with challenging behaviour may continue to do so over the course of their life to a greater or lesser extent. This behaviour is not something that can necessarily get ‘eliminated’, and that the presence of behaviour that challenges does not always require NHS intervention. Being actively open to services and requiring a practitioner should reflect a period in the person’s life, because of particular issues or severity, and not necessarily a ‘forever service’. |
| 1. 32 | The Challenging Behaviour Foundation | General comment | People needs to be replaced with children, young people and adults in the quality statements - using the term ‘people’ risks it being interpreted solely as ‘adults’ as most people assume people refers to adults. |
| 1. 33 | Voyage Care | General comment | * The standard sound good and would help improve the quality of life for those individuals with learning disabilities and behaviours that challenge. * The Quality standard seems reasonable and common sense and the gold standard that we would want to achieve. * · Whilst these seem to represent the gold standard, I am not sure how this will be achieved in current reality. I find that local teams are significantly understaffed and lack experience in relevant field, for example, some people we support do not have an assigned case worker (as it is seen one is not needed unless there are major issues and in some cases even then it is hard to get one assigned), majority of local teams work on crisis management rather than prevention (which is what these standards seem to be more reflective of, prevention). I have met many case workers, who have no experience in LD and so have complete lack of understanding of PWS. I feel the achievement of these would be very difficult unless something significantly changes in adult social care. |
| 1. 286 | 2gether NHS Foundation Trust | Question 1 | We noted an emphasis on statutory services, with little mention of direct care providers, who also require more specialist training, support and infrastructure to work within in order to provide good quality care to such a complex group of service users. We felt that minimum standards regarding staff training at this level would be helpful, along with requirements regarding working with statutory services and following guidance and advice offered by professionals. |
| 1. 287 | ADASS | Question 1 | There could be a benefit in there being a statement which emphasises the need for earlier intervention and prevention services so that people whose behaviour may challenge can have access to better support from an early age. Statement 3 emphasises support in the event of a crisis, but is less clear about prevention and early intervention as a whole. |
| 1. 288 | NHS England (I) | Question 1 | Yes, it aligns well to our key priorities within the NHS Long Term Plan for people with learning disabilities  <https://www.england.nhs.uk/long-term-plan/>  Whole life approach: this requires not just health services (universal and as well as specific to learning disabilities) to join up but also other departments in the Local Authority including social care, education and housing. It also needs a family centred, person centred, proactive and socially inclusive approach |
| 1. 290 | 2gether NHS Foundation Trust | Question 2 | We felt that locally we are in a position to be able to collect data and report on the majority of the measures listed in the document. |
| 1. 291 | ADASS | Question 2 | Systems for data collection are already stretched in many areas support services have been reduced in order to protect direct services when budget reductions are required. The emphasis on local data collection may result in a patchy response particularly if new data sets are required. |
| 1. 292 | NHS England (I) | Question 2 | ‘Ask Listen Do’ is a call to action campaign launched in October 2018 by NHSE. It arose from the poor experiences people with learning disabilities often report when giving feedback, raising concerns and making complaints. https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/  The campaign is supported by key stakeholders, patient and family groups and the voluntary sector. It is designed to increase the voices of children, young people and adults with learning disabilities and/or autism and their families, to ensure organisations actively ask, listen to and learn from their experiences of using services. |
| 1. 293 | 2gether NHS Foundation Trust | Question 3 | We feel that the statements in the draft quality standard are achievable but would like to see clear criteria for who will be held accountable for each, with targets being set for commissioners, providers or both as appropriate. |
| 1. 294 | ADASS | Question 3 | A named lead practitioner for all people with behaviour that challenges will be difficult to achieve within existing staffing resources, whether that be a named social worker or named lead health practitioner.  Similarly, the development of comprehensive specialist behavioural support in the community within existing resources will require a significant resource shift away from hospital-based services. There needs to be forward funding - pump priming - to create sustainable community-based systems prior to resources being released through disinvestment in beds. |
| 1. 296 | NHS England (I) | Question 3 | The NHS Long Term Plan for children, young people and adults with learning disabilities with behaviours that challenge includes a focus on enhancing and building community capacity to offer the support and care required in the community wherever possible, and to offer alternatives to the use of psychotropic medications as the sole means of managing behaviour. Additional resources will be made available from the NHS as part of the Long-Term Plan, but much of the care and support package will rely on a preventative, proactive, person-centred approach; social care, education and third sector providers, as well as capacity within the family. |
| 1. 297 | Surrey & Borders Partnership NHS Foundation Trust | Question 3 | Respite services for people who display behaviours that challenge are extremely limited. |
|  | ADASS | Question 4 | Similarly, the development of comprehensive specialist behavioural support in the community within existing resources will require a significant resource shift away from hospital-based services. There needs to be forward funding - pump priming - to create sustainable community-based systems prior to resources being released through disinvestment in beds. |
| 1. 298 | Future Directions CIC | Question 4 | Makes sense to combine the exiting LD: CB quality standard with this one. |
| 1. 299 | NHS England (I) | Question 4 | We welcome the system approach within this guidance and expect this to be considered as Integrated Care Systems evolve and mature. |
| 1. 300 | Royal College of Paediatrics and Child Health | Question 4 | It is agreed that the learning disorders/challenging behaviour QS should be integrated with this standard, this would be helpful and avoid a plethora of standards on similar topics |
| 1. 301 | Salutem Healthcare | Question 4 | The quality standards in this consultation 1-5 inclusive would benefit from being integrated into the existing standard learning Disabilities: Challenging Behaviour to minimise overlap and duplication, increasing transparency and accountability. |
| 1. 36 | 2gether NHS Foundation Trust | Quality statement 1 | We feel that further clarity is required regarding the positioning and role of the Lead Commissioner across services, especially with regards to their links with other commissioners (e.g. children’s services, mental health, autism, education) as although a specialist overseeing all services sounds positive in principle, we could foresee difficulties in providing a fully joined up service if these posts sits in isolation. |
| 1. 37 | 2gether NHS Foundation Trust | Quality statement 1 | We were not sure about the appropriateness of measuring rates of admission as a way of monitoring the outcomes of the role of Lead Commissioner as sometimes people are unwell and the safest place for them to be is in hospital. At other times there is a breakdown in community provision, which can happen for a multitude of reasons, and whilst a Lead Commissioner would have oversight at a higher level, it may not be possible to avoid all such breakdowns. |
| 1. 38 | ADASS | Quality statement 1 | A single commissioner across children & adult services may be difficult to achieve in all instances. A quality standard that requires a single commissioning board covering adult and children commissioning would be more achievable and take account of differing organisational structures across 152 separate local authorities. |
| 1. 39 | ADASS | Quality statement 1 | The rationale could be achieved through a single or joint commissioning board as much as with a single lead commissioner. |
| 1. 40 | ADASS | Quality statement 1 | The measures might include evidence of creating a single or pooled budget which aims to reduce the risk of discontinuity of commissioning decisions during transition from children to adult services. |
| 1. 41 | British Association of Social Workers | Quality statement 1 | This statement refers to the lead commissioner having experience working with people with a learning disability – it would be beneficial to expand upon this in order to ensure that person has relevant experience and an underpinning value base. It would be essential for this person to understand social care and best social work practice with adults who have learning disabilities. Ideally a commissioner who is a registered social worker with expertise and commissioning experience . |
| 1. 42 | British Association of Social Workers | Quality statement 1 | This section states that the lead commissioner will ensures that services and planned and delivered in a way that is co-produced with children young people, adults and their families. It will be important to define co-production or signpost to existing NICE guidelines. |
| 1. 43 | Contact | Quality statement 1 | Contact agrees with the statement as a key area of quality improvement.  However, without an allied quality standard for Learning Disability as a whole, the joint lead person as specified by this quality standard could become a Lead Commissioner for people with a learning disability and behaviour that challenges only. This could then reduce the impact of a joint Lead Commissioner by reducing the ability to bring together the commissioning across different agencies.  Joint commissioning between education, health and social care is a key requirement of the Children & Families Act which has been difficult to implement meaningfully. Ofsted/CQC local area inspections are frequently finding poorly developed joint commissioning arrangements.  The NNPCF recently surveyed parent carer forums and results found little evidence of shared priorities that would lead to effective commissioning. Forums said that local needs informed priorities in a minority of local services (42% in education, 30% social care and 23% health). |
| 1. 47 | Contact | Quality statement 1 | If the quality standard is for children, young people and adults, there needs to be and addition to this outcome measure that enables parent carers of children & young people to feedback on their satisfaction with services, ideally including a reference to parent carer forums as a route to gather feedback. |
| 1. 48 | Derbyshire County Council | Quality statement 1 | This statement should not be difficult to measure. However, this could potentially lead to some conflict between the local authority and Commissioning body if the post is not jointly funded. |
| 1. 49 | Future Directions CIC | Quality statement 1 | Think you will struggle to find a lead commissioner who has the experience highlighted i.e. in-depth knowledge and experience of working with children, young people and adults with LD including those who are at risk of developing behaviours that challenge. |
| 1. 50 | Future Directions CIC | Quality statement 1 | Is there something about Commissioners having an overview of any restrictive practices (MCA) in use, including the use of antipsychotic medication (STOMP). |
| 1. 51 | Future Directions CIC | Quality statement 1 | That service planning is also based on best practice / research. |
| 1. 52 | Future Directions CIC | Quality statement 1 | To receive feedback from people who use services can be difficult as it needs to represent all people and evidence of quality of life, employment, what validated measures will be used thinking of similar to Improving Access to Psychological Therapies (IAPT)  measures such as work and social adjustment scale (WSAS). |
| 1. 53 | Future Directions CIC | Quality statement 1 | Question 3: will need to be more investment in advocacy services |
| 1. 54 | Home From Home Care Limited | Quality statement 1 | This is not a new proposal. Please see the letter dated February 2012 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/215183/dh\_132482.pdf  It makes clear that a lead commissioner is appointed between the NHS and Local Authorities. If this has never happened, then it would be worth exploring why rather than making the same recommendation.  The proposal does not take account of the complexity of what and who does the commissioning. NHSE commissions Tier 4 CAMHS and High and Medium Secure services. CCGs and Local Authorities could commission through one joint commissioner but only for community-based provision. Local Authority staff cannot commission hospital services. |
| 1. 56 | Ludlow Street Healthcare | Quality statement 1 | It would be helpful to have guidance on the specific tool/s that should be used for this purpose to avoid bias in measure selection or the production of bespoke tools that are not valid or reliable. |
| 1. 57 | Ludlow Street Healthcare | Quality statement 1 | Awareness of intervening variables (e.g. local deprivation, local vacancy rates, use of part 3 orders) need to be viewed alongside these statistics to make them meaningful. Application of part 3 orders that enforce inpatient admission are not in the gift of commissioners and so there is a risk that services could be assessed negatively when admission rates are not reflective of operational issues. |
| 1. 58 | Mencap | Quality statement 1 | Pg. 5 - Must have experience in implementing positive behaviour support (if it is just asking for ‘experience’ they may just have experience in commissioning placements in ATUs). If they haven’t got a history of PBS, they are unlikely to commission it.  Quality measures: Re: Structure b) Include: in-depth knowledge around PBS. Define: knowledge of ‘local services’.  Re: Outcomes a) Self-reported level of satisfaction with services among people with a learning disability.  Comments: - Need to be clear what this is looking at - satisfaction with what? Looking at satisfaction about ‘experience’ is not a good measure. To illustrate – if someone has been locked in an ATU for many years, anything will be preferable and the person may say they are very satisfied (because in comparison where they are now is great. However, that doesn’t mean the new place is high quality/ in line with best practice).  - Suggest it should be satisfaction with ‘quality of the service’ e.g. safety, stability of staff team, following regulations at the service level. As well as satisfaction with ‘practice’ e.g. how the person is treated, staff turn up when they are meant to, they show an interest in the person etc.  - Some people may not be able to self-report, so families and advocates should be able to report as well.  - Indicators around quality of life should be used – i.e. access to the things that are important to us all.  Re: Outcomes b) Rates of inpatient admissions for people with a learning disability  This is a very limited measure. These are important:  - Time between when a person is identified as ready for discharge (for example through a CTR) and when they are actually discharged  - Reasons for delayed discharge  - Development of specific elements of the community support set out in the NHSE Service model eg. 24/7 intensive support service  - Waiting times etc.  - Average length of stay  - Information gathered in CTRs should be analysed for commissioning purposes  Broken down by children, young people and adults –to help understand the gaps in community services  Pg. 7 Welcome focus on ‘whole life approach’ and ‘ensures that local authorities and clinical commissioning groups take joint responsibility with service providers and other organisations for managing risk’.  We know areas where there is a shared approach to managing risk and this works well. |
| 1. 65 | National Network of Parent Carer Forums (NNPCF) | Quality statement 1 | The NNPCF agree that this draft quality standard accurately reflects a key area for quality improvement.  A key requirement of the SEND code of practice is that local areas develop shared priorities and jointly commission services based on these priorities. A recent survey of parent carer forums found little evidence of shared priorities that would lead to effective commissioning. Forums said that local needs informed priorities in a minority of local services (42% in education, 30% social care and 23% health).  Forums tell us that progress in joint commissioning is slow and difficult; there is widespread lack of understanding of personalisation and what it can achieve and individuals and leaders across the system are not yet committed to it as a new way of working. This particularly the case for joint commissioning across children’s and adult services. |
| 1. 67 | NHS England | Quality statement 1 | Self-reported level of satisfaction with services may not accurately reflect the effectiveness of role of lead commissioner.  It could be improved by reported audits from service providers as an evidence of effective delivery of services. |
| 1. 69 | NHS England (I) | Quality statement 1 | Could we also use training logs to ensure commissioners have the right knowledge, attitudes, skills and behaviours as well as the experience (made explicit in job descriptions)?  A lead commissioner, with the right experience (mind set and skill set) to take a strategic, system-wide approach to whole life pathways is welcomed, but it may be difficult to find such a person. This should also be a substantial role, crossing over children, young people and adult services. It is not a one day/half day part of a wider job description. |
| 1. 71 | NHS England (I) | Quality statement 1 | Rates of inpatient admission: should this be use of inpatient services rather than admissions, as length of stay and ability to discharge are also indicators of a well-functioning commissioning system  There is no national mandate around pooled budgets even though we'd strongly encourage it, so could read ‘should work towards’ pooling of resources wherever possible?  Pg. 7, third bullet point: and promotes personalisation and choice  Pg. 7 4th bullet point: co-production between children, young people and adults who use services, their families/carers and advocates … as well as with providers and commissioners |
|  | Pennine Care NHS Foundation Trust | Quality statement 1 | We are pleased that this statement describes integrated commissioning arrangements with a lead person which is always helpful in overcoming responsibility for funding. |
| 1. 75 | Royal College of General Practitioners | Quality statement 1 | There needs to be clarity at what level the joint commissioner is positioned in both organisations. This will need to be at board level to affect change. |
| 1. 76 | Royal College of Psychiatrists | Quality statement 1 | It is suggested that local authorities and clinical commissioning groups jointly designate a lead commissioner to oversee strategic commissioning of health, social care and education services specifically for all children, young people and adults with a learning disability, including those who display, or are at risk of developing, behaviour that challenges in the whole region overseeing community services, inpatient, low and medium secure services to have a broad overview.  The role of the lead regional commissioner needs to be well defined, duly resourced from new resources, with the necessary admin support and office space. |
| 1. 78 | Salutem Healthcare | Quality statement 1 | This standard is a key area for Improvement, however it could articulate the key functions of the post further. We welcome the necessity for strategic oversight but would like to see this expanded further to encompass leadership in long term innovation and proactive development of community based placed options for people. At this moment in time conversations can be reactive with an interest in short term savings as opposed to the long term aspirations and recovery for an individual or group. |
| 1. 79 | Salutem Healthcare | Quality statement 1 | Self report measures are a useful tool but often exclude a large portion of the target population who, by in large, have significant challenges with self advocacy and have been denied the opportunity to develop their voices and vocabulary to engage in such a process in a meaningful way. An inclusive and trusting process would ideally include wider advocacy that seeks to engage all supporters, including those who may struggle to engage with large formal events and also need time and trust to advocate effectively. |
| 1. 80 | Surrey & Borders Partnership NHS Foundation Trust | Quality statement 1 | Pooled budgets would be extremely helpful and reduce ‘silo’ working. It could be very difficult to find a Commissioner with experience of working with both children and adults in this field. |
| 1. 81 | The British Psychological Society | Quality statement 1 | We recommend gathering data about the reality of employment of such a commissioner with relevant experience and not just that it is specified in the role description.  Seeking outcomes, including self-reported level of satisfaction with services among people with learning disabilities, is to be commended. However, views from families and carers as well as professional staff should be collected, which would allow the level of satisfaction with services to be triangulated. We would recommend that people with learning disabilities should be told that there is a link between the commissioner and services commissioned. |
| 1. 83 | 2gether NHS Foundation Trust | Quality statement 2 | We agree with this idea in principle but again feel that further clarity is required regarding where this role would sit as the Lead Professional would need appropriate qualifications and experience, as well as a recognised level of authority and the ability to make decisions and influence budgetary demands based on clinical recommendations and family views.  We felt that there would need to be a very clear description of the job role, that all agencies fully sign up to for this to work; there would need to be a system wide acknowledgement and agreement on the level of influence across different systems if this role is to take on more than the existing care coordinator role (which has a largely internal function). |
| 1. 85 | 2gether NHS Foundation Trust | Quality statement 2 | From our perspective as a health provider, we felt that this role could sit within the Community Learning Disabilities Team (CLDT) and need not be limited to Community Learning Disabilities Nurses but robust joint working structures would need to be in place for this to be effective. |
| 1. 86 | ADASS | Quality statement 2 | This is an important standard and could be clarified further to include a single lead practitioner who is assigned to the individual to cover the transition period between children’s services and adulthood. It is during that crucial period that continuity for the person with needs as well as their families is particularly critical. |
| 1. 87 | British Association of Social Workers | Quality statement 2 | BASW England support the need for a named lead practitioner which is essential for co-ordinated care and support and reflects the need for relationship based social work practice. This statement reflects learning from the Named Social Worker Pilot Programme – the evaluation report is available at https://www.scie.org.uk/social-work/named-social-worker BASW England is also currently developing a Capability Statement for Social Work with Adults who have Learning Disabilities and during the consultation adults who have learning disabilities were consistent in stating that it is important that they know their social worker and have the opportunity to build a relationship. Further information is available at:  https://www.basw.co.uk/media/news/2018/dec/basw-england-and-ripfa-develop-professional-capabilities-and-cpd-social-work |
| 1. 88 | British Association of Social Workers | Quality statement 2 | This section outlines social workers in disabled children’s teams and community learning disability teams however it is important to include that social workers working in transition teams and with adults who have learning disabilities may be placed in wider adult social care teams including integrated health and social care teams. |
| 1. 89 | Contact | Quality statement 2 | Contact agrees with the statement as a key area of quality improvement.  Lead practitioners and keyworkers have been shown to be beneficial to families with disabled children but are still not consistently commissioned. A key working approach is also mentioned in the SEND Code of Practice to enable “holistic provision and co-ordination of services and support”.  However, it needs to be clear what the lead practitioners role is and that this is measured specifically. Having a named lead by itself is not going to improve outcomes, but coordinating care and support, understanding an individual’s (and their families) needs and aspirations, can improve outcomes, both individually and across the local area. |
| 1. 92 | Contact | Quality statement 2 | Again – need the addition of “family-reported level of satisfaction” with services to enable parent carers to have a voice about the quality of services. Especially as the named lead will be working with the parent carers as well as the child or young person. |
| 1. 93 | Derbyshire County Council | Quality statement 2 | Slightly more difficult to measure as not everyone will request this – or should it be routinely offered to people? Again, conflict may arise as to who should take on the role of named lead practitioner (i.e. should it be a health or social care member of staff)? |
| 1. 94 | Future Directions CIC | Quality statement 2 | Relationships - the practitioner must be active; someone who can get to know the person, their family circle or support network. |
| 1. 95 | Future Directions CIC | Quality statement 2 | In order to develop and review support and care plans think within this section it needs to reference within appropriate skills and knowledge an understanding of behaviour and behavioural analysis, Positive Behavioural Support (PBS), learning disability and ASD etc. They may only need to co-ordinate plans by using other specialist people / services but they still need to understand what’s going on make things happen and/or build confidence with others. |
| 1. 96 | Future Directions CIC | Quality statement 2 | Equality & Diversity Section: Should reference the Royal College of Speech & Language (RCSLT) Therapist 5 Good Communication Standards here. |
| 1. 97 | Future Directions CIC | Quality statement 2 | General Comment - What goes around comes around CB support teams by any other name which were disbanded by the NHS some time ago due to cost pressures. |
| 1. 98 | Future Directions CIC | Quality statement 2 | Needs to be clearer about who would and would not warrant a named lead practitioner; what is the criterion, level of CB? Will be the person ‘who shouts the loudest’ so only when in crises and we want to be proactive rather than reactive. |
| 1. 99 | Future Directions CIC | Quality statement 2 | As part of support and care planning people who have CB support needs should have a Behavioural Formulation that contributes or supports the care / support plan. |
| 1. 100 | Future Directions CIC | Quality statement 2 | Question 3: Needs to be more investment in Speech & Language Therapists or Associate S&LT Roles as there is a shortage so will be waiting lists. |
| 1. 101 | Home From Home Care Limited | Quality statement 2 | The principle is laudable, but the definitions of the named lead practitioner are too limited. The assumption here is that every person with a learning disability and behaviours that challenge is engaged with the statutory services.  Additionally, we know that the number of learning disability nurses in the NHS has hit a record low, plummeting by more than 40% in less than a decade. The latest statistics from 2017 show 3,192 learning disability nurses were working in hospital and community health services in England in June – the lowest since the NHS Digital records began in September 2009 when 5,553 were employed.  There remains a chronic shortage of children’s social workers across the UK. There are a significant number of vacancies across adult services in England with a focus on learning disability and autism.  The named lead practitioner should be extended to relevant social care workers in provider agencies. |
| 1. 105 | Lancashire Care NHS Foundation Trust | Quality statement 2 | If it is accepted that all people with LD and behaviour that challenges will require a named lead practitioner then it also needs to be accepted that this person may change over time according to who has the best skills knowledge and role at that time to co-ordinate care as a named lead practitioner. |
| 1. 106 | Lancashire Care NHS Foundation Trust | Quality statement 2 | Should additional data source be unpaid carers self reported level of satisfaction with services e.g. a placement provider satisfaction with community team involvement |
| 1. 107 | Lancashire Care NHS Foundation Trust | Quality statement 2 | If it is accepted that all people with LD and behaviour that challenges will require a named lead practitioner e.g. community LD nurse this will require significant investment and shift of focus from episodic care and referral based care to long-term involvement. This could not be absorbed into current capacity of community LD team professionals. |
| 1. 108 | Lancashire Care NHS Foundation Trust | Quality statement 2 | Good principle but how this will work may be difficult to implement (see comments below re quality statement 2) |
| 1. 109 | Lancashire Care NHS Foundation Trust | Quality statement 2 | If this is relevant to all types of providers from different organisations e.g. care provider, social work team, community LD team, whilst a good idea it may be difficult for one organisation to have responsibility over another without a formal process to do this i.e. similar to CPA framework. A community team may make a recommendation but the service provider may not follow this making it difficult for the community team named lead practitioner to deliver goals/actions, or vice versa the community team may not have capacity to meet the identified needs if the named lead practitioner is the care provider’s line manager of placement. |
| 1. 110 | Lancashire Care NHS Foundation Trust | Quality statement 2 | Structure a) data source. Data would only be available for current open caseload of community LD team professionals with regard to clients with LD and behaviour that challenges. There may be a number of others with behaviour that challenges not currently open that may require named lead practitioner and this information may not be easily available from GP records.  Placement providers may also need to supply this information to ensure all are captured. |
| 1. 112 | Lancashire Care NHS Foundation Trust | Quality statement 2 | Do all adults and/or children with LD and behaviour that challenges require a named lead practitioner from LD team or in some cases should this be a trained practitioner within the provider where the person lives or is delivered care e.g. care provider/placement? |
| 1. 113 | Lancashire Care NHS Foundation Trust | Quality statement 2 | If it is accepted that all people with LD and behaviour that challenges will require a named lead practitioner according to who has the best skills knowledge and role at that time to co-ordinate care as a named lead practitioner, then all professions will need investment to increase capacity within community LD team to take on this role and to meet holistic needs of adults proactively and responsively i.e. Specialist LD SLT and other LD AHP roles, LD clinical psychology, and LD community nursing |
| 1. 114 | Mencap | Quality statement 2 | Pg. 8 The co-ordination by a named lead practitioner is a good thing (follows the approach that is used well in CPA)  We suggest there is another quality measure that is about:  ‘People with learning disabilities, their families and other people who offer support are able to access the names and contact details of named lead practitioners in an area.’  Pg. 9 There is some confusion in the first statement (about service providers) as this implies that they will ensure that lead practitioners are in place. We think this should be the lead commissioner’s role. It may be that the statement is highlighting that service providers are working with the lead practitioner. It would be helpful if this could be clearer.  It would be helpful to be clear that the health and social care practitioner needs to co-ordinate the PBS plan as well. The standard says the lead practitioner has appropriate skills and knowledge. It would be good to be clear that the lead practitioner needs to be experienced in PBS.  Need to be clear that PBS plans are not the only plan that may need to be developed (for example if someone has a Mental Health need as well then just using PBS may not work).  If commissioners are ensuring that no decisions are made without the lead practitioner, this again reinforces the need for both roles to have be skilled in PBS.  Note: it has an implication on resources if no decisions can be made without the lead practitioner (what is their case load).  Pg. 9 – same comments as for quality standard 1 in relation to using self-reported satisfaction as an outcome.  Definitions are really helpful, however it highlights that there may be resource implications (developing a relationship with the person, and coordinating meetings may take more resources than are currently offered. It would also be important that this named person was sustained over time, i.e. not just a named person but the same named person). It would be helpful to define what regular meetings means in practice e.g. monthly/quarterly/ yearly?  Equality and diversity statement - there is no reference to other carers beyond the family. |
| 1. 124 | National Network of Parent Carer Forums (NNPCF) | Quality statement 2 | The NNPCF agree that this draft quality standard accurately reflects a key area for quality improvement.  There is evidence to show that families value a named lead practitioner who acts as a single point of contact. Forums report that face to face support and communication from LA throughout the EHC Needs assessment process can makes a real difference. |
| 1. 126 | NHS England | Quality statement 2 | This statement may be hard to measure because named practitioners for one organisation may not be linked up with primary care/GP practices. It could be improved by adding lead practitioner and named practitioners in each service.  GP practices may not keep coded data about lead practitioners involved in the care of patients. |
| 1. 128 | Royal College of Occupational Therapists | Quality statement 2 | Named Lead Practitioner – This is a very good idea, but the Lead Practitioner could also be an Occupational Therapist working in community learning disability team or in children’s or adult’s disability teams |
| 1. 129 | Royal College of Speech and Language Therapists | Quality statement 2 | We are pleased to see the acknowledgement of the need for speech and language therapists in the equality and diversity considerations. We would however, encourage a change to the language to ensure SLTs are involved, as well as family members, to:  ‘This may include involving speech and language therapists or AND working with family members on finding solutions to allow for effective communication’. |
| 1. 130 | Salutem Healthcare | Quality statement 2 | We welcome this standard, however believe it could go further in articulating continuity of delivery. In our experience the patchy allocation of current named practitioners (or equivalent) is often episodic. Disruptive of long-term planning and building trusting relationships for effective advocacy. Similarly, although the standard refers to review and regular meetings, it does not set a (minimum) standard for frequency allowing for resource driven and inconsistent delivery. |
| 1. 131 | Salutem Healthcare | Quality statement 2 | We believe this Statement maybe hard to deliver using current resources. As a private sector provider we often struggle to find a consistent named statutory practitioner and if we do, they often do not have the requisite experience, specialism or relationship with the person that allows the multiagency process to move forward confidently or with any great momentum. |
| 1. 132 | Surrey & Borders Partnership NHS Foundation Trust | Quality statement 2 | Lead practitioners can be a good way to ensure people have their needs met and providers are accountable. However, this assumes that individuals continue to show behaviours that challenge on a consistent basis, which is often not the case. Practitioners cannot keep people on their caseloads indefinitely, but perhaps teams need to be prepared to accept re-referrals for behaviours that have not been seen for long periods, to ensure PBS plans and other care plans are updated in a timely way. |
| 1. 133 | The British Psychological Society | Quality statement 2 | It needs to be made clear that what is being recommended here is not specifically a health practitioner but includes social workers and therefore reflects a return to integrated community learning disabilities teams.  It would be useful to suggest that the role is open-ended or at least for a minimum time. Particularly from a trauma-informed care perspective, it would be helpful for the role to be in place for as long as that practitioner is in post, with transition to a new named lead practitioner needing to be done slowly with joint working. This will be more resource intensive but would address attachment needs and reduce impact of trauma.  Overall, we welcome the idea of assigning lead practitioners. However, we have would like assurances that all professionals in the role of a Health and Social Care practitioner have the knowledge and skill base to understand what type of support a person with a learning disability should have. This would include person centred planning or Positive Behaviour Support (PBS) and sufficient training in the use of simple compensatory aids such as Picture Exchange Communication System (PECS), Alternative and Augmentative Communication (AAC), Occupational Therapy support tools, Speech and Language Therapy (SALT) supports, communication, Active Support and Sensory needs.  It may be more appropriate for the lead practitioner to be a named responsible practitioner with a qualification in understanding and supporting people with learning disabilities. This should be something which is developed in line with the British Institute of Learning Difficulties (BILD) such as the training advised in the Positive Behaviour Support (PBS) competencies framework (e.g. Professional Diploma Level 5). This would be essential if, as the guidance states, ‘they develop and review the care and support plan’.  The restriction on who can be a lead person to a Health and Social Care practitioner may not be the best person-centred choice for some service users. Regardless of the financial implications and the fact that it is often deemed necessary for the funding agency to be the lead practitioner, it is often the service provider who knows the client well so they may need to be included on this list.  It needs to be clarified who would act as the lead practitioner for people with a learning disability in secure services. |
| 1. 139 | The Challenging Behaviour Foundation | Quality statement 2 | We strongly agree with this quality statement. However, the statement should include that the lead practitioner will have appropriate experience, skills and knowledge to be the ‘lead practitioner’. It needs also to include what they will do i.e. to co-ordinate and facilitate access to support and services.  Additional information needs to be included around the necessary experience, skills and knowledge of the named lead practitioner to fulfil this role for example level of knowledge / skills in positive behaviour support |
| 1. 141 | Voyage Care | Quality statement 2 | My only thoughts really are the reality of these with regards to resources i.e. a named practitioner – our experiences are even when individuals do have a named care manager as soon as they are settled they go on to the duty team or people move on who have built those relationships with individuals, specialist behavioural resources within the community – these are often very limited and lacking in resources and or waiting lists are long and finally where to live again is often limited to the available resources and provisions/providers available. I do agree with all the quality standards however it is achieving them in this time of underfunding and scant resources. |
| 1. 142 | 2gether NHS Foundation Trust | Quality statement 3 | We obviously agree with this in principle but are interested to see how the measurements and outcomes for this standard will link with the previous two standards. The responsibilities of the Lead Commissioner and Lead Professional will need to clearly outline the responsibilities around family and carer support, as well as an element of accountability. |
| 1. 143 | 2gether NHS Foundation Trust | Quality statement 3 | We wondered about the process of auditing whether or not families and carers have been involved in the development of support plans as this may not always be explicitly stated in existing plans. |
| 1. 144 | 2gether NHS Foundation Trust | Quality statement 3 | We were not sure about measuring the outcome of this standard by counting the number of people with learning disabilities who live in their own homes or at home with family, as even with full family and carer involvement in care planning the decision may still be made for the service user to move to a supported environment meaning that this measurement may not be a true reflection of the outcome of this standard. |
| 1. 145 | ADASS | Quality statement 3 | Evidence from case notes should be able to demonstrate that there are recorded meetings involving families and carers. |
| 1. 146 | ADASS | Quality statement 3 | Involvement of families and carers is important. However, there is also a need to ensure that advocacy is available to the person. This is particularly important in instances where either there is no active involvement of family and/or carers, or where there are conflicting views around what is in the best interests of the person with behaviours that challenge.  In addition, there should be corresponding Quality Standard which ensures that the person themselves is involved in their support planning, and that ‘reasonable adjustments’ are made to ensure that people with LD can be involved as much as possible in line with Mental Capacity Act requirements. |
| 1. 148 | British Association of Social Workers | Quality statement 3 | This section again outlines community learning disability teams and children’s services however would benefit from wider adult social care teams being included (as above). |
| 1. 149 | British Association of Social Workers | Quality statement 3 | This section does not include consideration of situations which arise out of hours which may require contingency planning as the majority of services are limited or unavailable. |
| 1. 150 | Contact | Quality statement 3 | Contact agrees with the statement as a key area of quality improvement.  Person centred care is again central to the Children & Families Act and parent carers tell us that more needs to be done to embed the culture that underpins the principles of the Children and Families Act (Section 19 Principles). At an individual level, not enough local authorities, health commissioners and schools are working in a way that places the wishes of children, young people and their families at the heart of services. Co-production with families and joint working across agencies to wrap services around families in an effective, person centred way remains an aspiration rather than a reality in most areas. |
| 1. 152 | Derbyshire County Council | Quality statement 3 | This should not be too difficult to measure. Co-production could and should be evidenced in any service area development. Contingency plans need to be in place for all. |
| 1. 153 | Future Directions CIC | Quality statement 3 | In terms of care and support planning should there be something the monitoring of any restrictive practices (MCA) in use, including the use of antipsychotic medication (STOMP). |
| 1. 154 | Future Directions CIC | Quality statement 3 | Psychological support how is this measured |
| 1. 155 | Future Directions CIC | Quality statement 3 | Prevention of Crisis: been here before with this idea which has never really managed to get off the ground the answer historically has been for families to be left to get on with it or transfer to out of area hospital or private residential care. To make it work you will need investment in additional out of hrs support similar to some of the things happening within the NW around Transforming Care Support Teams. Respite support and care services will have to have the right skills and knowledge to support someone either within the family, own home or away from their home in a purpose built provision. |
| 1. 156 | Future Directions CIC | Quality statement 3 | Needs to be something about training in this section for staff and families i.e. understanding behaviour, PBS including keeping themselves safe, communication, active support etc. ‘Exerts by experience’ (people Supported and families) involved in the delivery. There is a need for the training to be standardised. Maybe needs to be linked to the learning disability core standard, the work currently under way by the DOH entitled LD and Autism training for health and care staff or the work underway around PBS. |
| 1. 157 | Home From Home Care Limited | Quality statement 3 | There is no methodology including costs set out for the collection of any meaningful data that demonstrates delivery. Some individuals have no family engagement for a number of reasons and this data needs to be collected. |
| 1. 158 | Lancashire Care NHS Foundation Trust | Quality statement 3 | Data would only be available for current open caseload of community LD team professionals with regard to people with LD and behaviour that challenges who have care and support plans and whether families and carers were involved in developing them. There may be a number of other people with LD and behaviour that challenges not currently open that may require or have care and support plans in collaboration with families and carers in place. This information may not be easily available from records. Placement providers may also need to supply this information to ensure all people are captured who have this in place. |
| 1. 159 | Ludlow Street Healthcare | Quality statement 3 | Definition of endorsement of family involvement on data collection needs to be clarified (e.g. 5 minute phone call vs attendance at CTR / CPA meeting). Suggest that this data is collected from families as well as from routine audit delivered by services to increase data quality. |
| 1. 160 | Mencap | Quality statement 3 | It would be helpful to define ‘carer’ – is this an unpaid carer or paid support staff?  Should it be ‘individuals, families and carers’ are involved in developing the care and support plan. Is this focusing on the PBS plan within the care and support plan?  The rationale section should refer to PBS and focus on supporting families and carers to develop their understanding of the purpose of behaviours and ways of supporting someone to cope at a time of crisis, as well as to find and learn alternative and more useful ways of supporting the person to get their wants and needs met. It would also helpful to include supporting the wellbeing of the family and providing them with coping strategies and support to help them manage in times of crisis (reflecting that this is traumatic for people).  Could this standard be about 2 different things – both important?  1. Supporting families who are caring for the person in the family home (to know information, increase confidence etc and be able to access the right services if/when they are needed?)  2. Ensuring that where someone is cared for outside the family home, their behaviour/ care and support plan is informed by the expertise/ involvement of the individual and the family – and is a better plan as a result.  How to prevent or respond to a crisis – this is likely to include being able to access services, so family and carers must be able to actually access the services. There could be an outcome around whether families are able to access the support set out in the care and support plan in a timely way e.g. around preventing/responding to a crisis. This is the same for all people supporting someone, not just families, e.g. the ability to access IST support out of hours.  P13 It would make sense to link the commissioner to the lead commissioner role. In service provider section, why is there a statement that has social care providers and residential care providers as different things. There should also be mention of people from education services (this quality standard is also for children and young people).  P14- In the Definitions section – it would be good if this links to the “outreach services” as opposed to the idea of inpatient ones. Also this suggests that there is no building of the families skills/confidence to be able to cope in the moment (if it were about social care services it would also need to include the idea that interventions used were least restrictive possible and followed the guidance of the restraint reduction network (BILD) code of practice about physical intervention and DH Guidance ‘Positive and proactive care’.  There could be some family-reporting of satisfaction with the quality of the care and support plan (and that it leads to the right support actually being given). There could be an audit of availability of appropriate respite services that meet the needs of the local population (as set out in the NHSE service model). |
| 1. 168 | National Network of Parent Carer Forums (NNPCF) | Quality statement 3 | The NNPCF agree that this draft quality standard accurately reflects a key area for quality improvement.  Parent carer forums tell us that more needs to be done to embed the culture that underpins the principles of the Children and Families Act (Section 19 Principles). At an individual level, not enough local authorities, health commissioners and schools are working in a way that places the wishes of children, young people and their families at the heart of services. Co-production with families and joint working across agencies to wrap services around families in an effective, person centred way remains an aspiration rather than a reality in most areas.  Parent carers tell us that good quality EHC Plans:  · are outcome focussed and person centred give a much better impression of the aspirations and needs of children and young people with SEND.  · are co-produced with families and young people and there is evidence that this is happening with some success across the country.  · made a difference in delivering the outcomes.  Special Educational Needs and Disability (SEND) Reforms Implementation Survey for Parent Carer Forums – Spring 2017 found that:  • 54% of forums report that parent-carers are fully or largely engaged in making decisions about their own SEND provision.  • Only 5% say they are poorly involved.  At a strategic level, partners must engage children and young people with SEN and disabilities and children’s parents in commissioning decisions, to give useful insights into how to improve services and outcomes. This ensures that commissioning decisions on services for those with SEN and disabilities are shaped by users’ experiences, ambitions and expectations. The SEND Code of Practice states that in order to do this, local authorities and CCGs should engage with local organisations including Parent Carer Forums. |
| 1. 173 | NHS England | Quality statement 3 | This statement may be hard to measure because multiple agencies are likely to be involved who may have their own care plans. |
| 1. 174 | NHS England | Quality statement 3 | The statement could be improved by suggesting proportion of adults who live in their own home or with their family with agreed care plan in place. |
|  | Pennine Care NHS Foundation Trust | Quality statement 3 | We are pleased that this statement actively promotes Person Centred working |
|  | Pennine Care NHS Foundation Trust | Quality statement 3 | We are pleased this statement includes families |
|  | Pennine Care NHS Foundation Trust | Quality statement 3 | It is good that this statement acknowledges that out of hours services are sometimes needed due to crisis or emergency arrangements/planning |
| 1. 175 | Royal College of General Practitioners | Quality statement 3 | This should involve the service user as well. Research shows service users appreciate various positive staff behaviours, most notably being 'kind'. They valued being helped, staff understanding what was important to them and staff making time for them. Participants also described behaviours that they did not value, including staff being too controlling, being too busy or not providing enough support and being disrespectful in how they spoke to them.  https://www.ingentaconnect.com/content/bild/ijpbs/2016/00000006/00000002/art00002 |
| 1. 176 | Royal College of Occupational Therapists | Quality statement 3 | Support for families and carers – it is good to see AHPs identified there. |
| 1. 177 | Royal College of Speech and Language Therapists | Quality statement 3 | It is unclear why the outcome for this standard is ‘Proportion of adults with a learning disability who live in their own home or with their family’ when the standard refers to the involvement of stakeholders in developing a support plan. This does not seem like a relevant outcome measure for this standard and we would strongly encourage amending this. |
| 1. 178 | Royal College of Speech and Language Therapists | Quality statement 3 | We recommend that you add allied health professionals to the list of health and social care practitioners. Allied health professionals, such as speech and language therapists, are a key professional supporting people with learning disabilities and their families in the community and should be referenced accordingly. |
| 1. 179 | Salutem Healthcare | Quality statement 3 | Currently Care Hours are often limited to direct support or training. Whilst there are fragile exceptions, Commissioners do often not support what can be considerable investment in proactive and meaningful engagement with wider circles of support. Expectations of ownership would need to be well articulated. |
| 1. 180 | Salutem Healthcare | Quality statement 3 | We believe this measure would be adequate but a quality tool would be beneficial to avoid a ‘tick box’ approach to compliance. |
| 1. 181 | Salutem Healthcare | Quality statement 3 | We welcome the emphasis on inclusive co-production of contingency and crisis plans that often require greater flexibility and investment to be effective. |
| 1. 183 | The British Psychological Society | Quality statement 3 | If the lead practitioner is responsible for designing the care and behavioural support plan, there needs to be a clear standard for what level of skills and training this person needs in order to undertake this task (e.g. in accordance with the BILD PBS competencies framework).  Rationale page 12: It may be relevant to draw on trauma-informed care ideas when considering the value of people with learning disabilities being supported to remain with families where possible. Families will need support that is preventative in nature and will at times of transition. Families will need support from advocacy family support organisations independent of services, although this may have some cost implications from a commissioning perspective.  Outcome page 13: The outcome does not reflect the quality statement as currently written. The quality statement is about involvement by services and it therefore seems that families and carers will need to say if they are supported as well as what support is offered.  How to respond in a crisis: It may not be appropriate to label what is required here as a solely person-centred plan. It seems that what would be most relevant would be more part of the behavioural support plan, which should certainly be person-centred in nature, including the (pro) active and reactive strategies component which would address how to respond in a crisis. This section should include prompts to a variety of changes required, not just to the environment. |
| 1. 186 | The Challenging Behaviour Foundation | Quality statement 3 | Alongside ‘developing’ a care and support plan, this statement needs to include that families and carers should be involved in implementing and reviewing the care and support plan.  Preventing or responding to crisis is likely to require family and carers having access to appropriate services in a timely way and there should be an outcome to reflect this.  Clarification is needed around the term carer – paid / unpaid. |
| 1. 189 | 2gether NHS Foundation Trust | Quality statement 4 | Whilst we agree with the need for 24/7 access to specialist support, we did wonder about also adding something to the standard about early access for assessment and / or intervention, which is equally important, if not more so. |
| 1. 190 | 2gether NHS Foundation Trust | Quality statement 4 | We feel that Speech and Language Therapists and Occupational Therapists should also included in the list of healthcare practitioners who provide specialist assessments for people with learning disability and behaviour that challenges in the community setting. The role of speech and language therapists have been described, but not the title, and there is no mention of occupational therapists nor physiotherapist (whilst other relevant professions are listed). |
| 1. 191 | 2gether NHS Foundation Trust | Quality statement 4 | We were less certain about the training element of this standard as we would like to see a wider array of training being considered here to ensure that people’s needs are being met in an holistic way. There was some concern that the emphasis could be placed on ABA / PBS style training, possibly at the expense of other areas such as trauma informed care, Autism Spectrum Conditions, physical health issues, sensory processing, etc. |
| 1. 192 | 2gether NHS Foundation Trust | Quality statement 4 | We were a little concerned to see that the outcome measures centred around people living in their own homes and admission rates as we felt that there are too many other variables at play meaning that, even with the very best training for the teams, circumstances could still arise where people require a stay in hospital or to be looked after somewhere other than their own home. We felt that using quality of life measures may be more appropriate to assess the quality of the service provided, which is much more likely to be influenced by the skill set of the staff involved. |
| 1. 193 | ABA Access4All | Quality statement 4 | I think it is left too vague as to what exactly the training is for the ‘specialist behavioural support - see bold underlined point below, p17 of draft standard.  Staff trained in ABA or PBS should be specified at this point. These are the people who redirected my son’s challenging behaviour, such that he can now stay at home with us and not get sent off to an ATU. Other staff, including Clinical and Educational Psychologists, just gave me generic common-sense advice that really I could have worked out for myself.  If you go cheap on the intervention at critical points, or choose the wrong staff, the expense to the state of residential care is immense. |
| 1. 196 | ADASS | Quality statement 4 | This is an important standard and needs to be backed up by a requirement for CCG commissioners to demonstrate that investment has been made in behavioural support services which are available to prevent – rather than at the point of - crisis. |
| 1. 197 | ADASS | Quality statement 4 | c) evidence that professionals working in specialist behavioural support are trained…..” this could specify or provide examples of appropriate training – e.g. PBS – that specialists should be expected to have received. |
| 1. 198 | British Association of Social Workers | Quality statement 4 | This section refers to availability of services 7 days per week however does not elaborate as to whether this includes bank holidays and provision during the evening and / or nights. |
| 1. 199 | Contact | Quality statement 4 | Our own research highlighted the waiting times of mental health services, with many waiting over a year for access to CAMHS. Many parent carer forums report that pressures on funding are causing local authorities to take short term decisions that impact the outcomes and life chances of children and young people with a learning disability and or autism. For example, forums report that the thresholds for receiving social care are being raised depriving many families of the early help they need including short breaks; this creates further pressures on resources. |
| 1. 201 | Contact | Quality statement 4 | Could there also be a ‘family reported’ satisfaction with services here too. The stress of trying to access services or support for their child can have a detrimental effect on parent carers. |
| 1. 202 | Derbyshire County Council | Quality statement 4 | This is also a little more difficult to measure – an Outreach team can be in place for example but does it cover 365 days a year, 24 hours a day? How can it evidence that it supports all people who require support in the community. Evidence of Positive Behaviour Support for individuals, families and providers can be measured and should be available. |
| 1. 203 | Future Directions CIC | Quality statement 4 | People and families who use services and families involved in the formulation of support and care plans and the delivery of any staff training. |
| 1. 204 | Future Directions CIC | Quality statement 4 | See 11 above about S&LTs |
| 1. 205 | Future Directions CIC | Quality statement 4 | Quality Measures: What about specialist service providers who support people with CH and evidence of specialist behavioural L&D? |
| 1. 206 | Future Directions CIC | Quality statement 4 | Equality & Diversity Section: as before should reference the RCSLT 5 Good Communication Standards here. |
| 1. 207 | Future Directions CIC | Quality statement 4 | Specialist training - how will this be benchmarked to ensure quality service? |
| 1. 208 | Home From Home Care Limited | Quality statement 4 | There is a chronic shortage of the staff with the skills needed to deliver the community-based interventions for children and adults and which will provide support for the family.  The better option here is to:  1. Train families and measure the numbers who successfully complete such programmes.  2. Train staff in care services (both residential and domiciliary) with the skills needed and measure the numbers completing the course.  In relation to 1 and 2 above recommend that the Department of Health & Social Care fund appropriately the training provision that is needed. |
| 1. 209 | Lancashire Care NHS Foundation Trust | Quality statement 4 | Good principle but this may need investment and training to ensure suitably skilled workforce to deliver this and clear whose responsibility it is to deliver this and shared ownership. Joint working to deliver specialist behavioural support with LD health teams, social care, education (child services), and providers of placements working together. |
| 1. 210 | Lancashire Care NHS Foundation Trust | Quality statement 4 | All professions will need investment to increase capacity within community LD team to take on this role and to meet holistic needs of adults proactively and responsively i.e. Specialist LD SLT and other LD AHP roles, LD clinical psychology and community LD nursing, in order to deliver specialist behavioural support in the community within a reasonable waiting time. |
| 1. 211 | Lancashire Care NHS Foundation Trust | Quality statement 4 | Clarity would be needed regarding service responsibilities for all agencies in relation to who is responsible for what and when in regard specialist behavioural support for people with LD and behaviour that challenges to be available 7 days a week. This is important so as to ensure services work together and responsibilities are clear for each team/service involved and commissioned to deliver this service. |
| 1. 212 | Lancashire Care NHS Foundation Trust | Quality statement 4 | Clarity would be required as to what constitutes a profession being trained in helping people with a learning disability and others to understand and change behaviour that challenges and how this will be measured |
| 1. 213 | Lancashire Care NHS Foundation Trust | Quality statement 4 | Data would only be available for current open caseload in relation to proportion of people with a LD and behaviour that challenges accessing specialist behavioural support. Some people with a LD and behaviour that challenges may be accessing this type of support within the organisation providing placement and/or have plans in place ( based on previous specialist behavioural support) that are still relevant from previous contact with a professional in community LD team, but this data may be difficult to collate.  Providers (school, families and carers, supported living placement providers etc.) may be able to evidence plans based on previous community team involvement. |
| 1. 215 | Ludlow Street Healthcare | Quality statement 4 | For this to be accurate the threshold for competencies needs to be associated with an accepted skills escalator model of skill mix. Not all competent practitioners are formally trained in behaviour support in respect of having post training qualification (e.g. some very experienced clinical psychologists with extensive experience in working in the ID specialism, or some experienced LD nurses). Also, some people with qualifications may not demonstrate competence. Suggest that audit of PDR and evidence of in vivo quality checks supplements straightforward training completion data. |
| 1. 216 | Mencap | Quality statement 4 | Pg. 15 –Ensuring that specialist support is available locally can help families and carers (again does this include paid support staff?) where the person lives.  Specialist behaviour support needs to be available 24/7 (and hands-on) – in line with NHSE service model (this will need increased resources).  It would be helpful to define this – does it include forensic community support (this would be in line with NHSE service model).  Waiting times for assessment have been set - is access to treatment and support locally set?  Evidence that professionals are trained - this needs to reference PBS and would also benefit from some reference to trauma (both as a potential origin of behaviours that may challenge and as an outcome).  P16 Service providers needs to reflect the increased costs in training teams. Needs to make clear that the specialist services that are available 7 days a week are not just social care providers, but the specialist support services.  Why are the health and social care practitioner not linked to the lead practitioner to ensure that the support is co-ordinated?  Need to consider the last sentence in this section “to reduce the behaviour that challenges, if it is causing problems for them…If it is challenging behaviour then surely it is causing a problem for them, if not, it is just behaviour. It also may be better to describe this as “find alternative more useful behaviours” (this same amendment needs to be applied to the section on people with a learning disability).  Under definitions - “*Support provided by practitioners who have training in helping people with a learning disability and their families and carers to understand and change their behaviour if it is causing problems for them or other people”* has the same issue. Also the description ‘change their behaviour’ may be better described as” find alternative more useful behaviours and to learn coping strategies”  Equality and diversity statement - there is no reference to other carers beyond the family. |
| 1. 226 | National Network of Parent Carer Forums (NNPCF) | Quality statement 4 | The NNPCF agree that this draft quality standard accurately reflects a key area for quality improvement.  In the last few months, the NNPCF have seen an increase in concerns from forums regarding local CAMHS services. This is supported by the findings of local area inspections by Ofsted and the Care Quality Commission.  Forums report that SEND is not a high priority for the majority of clinical commissioning groups. This means that many local health commissioners have not focussed on the requirements of the SEND reforms resulting in many practitioners not being aware of their responsibilities under the CFA 2014.  Families reporting shortages in key services such as CAMHS and Autism diagnostic pathways and services not delivered in a joined up and effective way.  Many forums report that pressures on funding are causing local authorities to take short term decisions that impact the outcomes and life chances of children and young people with a learning disability and or autism. For example, forums report that the thresholds for receiving social care are being raised depriving many families of the early help they need including short breaks; this creates further pressures on resources. |
| 1. 231 | Royal College of General Practitioners | Quality statement 4 | Consideration should be given to amending Statement 4 to ‘People with a learning disability and behaviour that challenges can have timely specialist behavioural support in the community’. |
| 1. 232 | Royal College of Occupational Therapists | Quality statement 4 | Services in the community – Occupational therapists, and also Speech and Language Therapists, should be named in the Health and Social Care professionals section. They are key in the assessment of communication and sensory needs that are often at the root of challenging behaviours. |
| 1. 233 | Royal College of Speech and Language Therapists | Quality statement 4 | We are pleased to see the acknowledgement of the need for speech and language therapists in the equality and diversity considerations; but again we would encourage a change to the language to ensure SLTs are involved, as well as family members, to  ‘This may include involving speech and language therapists or AND working with family members on finding solutions to allow for effective communication’. |
| 1. 234 | Salutem Healthcare | Quality statement 4 | We welcome this standard in driving up the skills and delivery of specialist teams, focusing on skilled and collaborative approaches. We whole heartedly agree with stake holder statement 11, by Skills for Care, regarding the lack of articulated and resourced expectations from all partner agencies, often resulting in blame soaked networks who react to crisis. |
| 1. 235 | Surrey & Borders Partnership NHS Foundation Trust | Quality statement 4 | This is very positive. The focus does need to be on increasing support where the person is, not on moving the person/giving notice/seeking hospital admission. This should include a Trauma Informed Care approach. Difficulties arise due to long NHS waiting lists, providers employing specialists that cover large geographical areas and lack of training/understanding of PBS and the Mansell ethos in the case of some providers (direct care / support staff).  There is an expectation that professionals are trained in helping people understand and change behaviour that challenges. There also needs to be a stipulation that provider agencies (e.g. in supported living services) have specialist training in Positive Behaviour Support and related topics. This needs to be competency based, not just online/classroom based/induction training. |
| 1. 237 | Sussex Partnership Foundation Trust | Quality statement 4 | It will be impossible within current resources and structures for the CLDT to provide behavioural support 7 days a week. This would require significant CCG investment and we wondered about a more generalised focus upon 7 day support building upon existing crises provision which may not currently call itself behavioural support.  In addition we think that the NICE guidance also highlights the need for access to psychiatry and appropriate physical health support 7 days a week |
| 1. 239 | The British Psychological Society | Quality statement 4 | There should be more focus on supporting the competencies of services that support people presenting with behaviour that challenges. Some of the services which take people on at discharge from assessment and treatment units or inpatient wards are more expensive than the beds from which the person has been discharged, but can vary widely in their level of competency. There are provider services which may position themselves as highly specialist but seem reliant on the NHS services to support the people they work with.  The statement needs to include crisis management before an in-depth behavioural assessment, which can take some time.  Evidence of jointly commissioned crisis support services, as well as in-depth longer term functional assessment and intervention from a Specialist Behavioural Support Service, is needed. For example a very quick assessment of physical health that might be having an impact and urgent social/health care provision, could include care staff going in with appropriate experience and training to reduce the need for restrictive interventions with augmented communication skills, Makaton and Intensive Interaction.  The statement could read ‘HCPC registered practitioner psychologists with specialised training in assessment of risk and need for people with a learning disability’. It should not be assumed that a psychologist has training in PBS and risk assessment for this client group. For example, Clinical, Forensic and Educational Psychologists undertake this as part of their core training, however, all practitioners should have undertaken specific BILD accredited PBS training and this should be the same for psychiatrists and social workers. Speech and Language Therapy (SALT) and Occupational Therapy input should potentially be included in this list.  The statement could read ‘HCPC registered practitioner psychologists with specialised training in assessment of risk and need for people with a learning disability’. It should not be assumed that a psychologist has training in PBS and risk assessment for this client group. For example, Clinical, Forensic and Educational Psychologists undertake this as part of their core training, however, all practitioners should have undertaken specific BILD accredited PBS training and this should be the same for psychiatrists and social workers. Speech and Language Therapy (SALT) and Occupational Therapy input should potentially be included in this list.  It needs to be made clear who is responsible for this role in secure services.  We believe that the outcome does not reflect the statement as currently written. |
| 1. 245 | The Challenging Behaviour Foundation | Quality statement 4 | This needs to include that specialist behaviour support should be available to the person with learning disability and behaviour that challenges and to their families and carers.  It would be helpful to add that Specialist behaviour support should be available for early intervention. |
| 1. 247 | 2gether NHS Foundation Trust | Quality statement 5 | We felt that this standard needed more weight behind it as measuring the availability of options and / or the presence of discussions about these options may not accurately reflect whether or not people actually felt heard or ended up living where they would wish. We also wondered about amending it to read “people are supported to have their views taken into account” to reflect the realism of practicalities and resources. |
| 1. 248 | 2gether NHS Foundation Trust | Quality statement 5 | We were interested in the notion of people living somewhere that “meets their needs” as this could be open to much interpretation and wondered if this needed tightening up to reflect whose views were being taken into account and also who assesses this. |
| 1. 249 | 2gether NHS Foundation Trust | Quality statement 5 | The role of specialist occupational therapists have also not been mentioned here. Although we recognise that an OT is not needed for every person who is moving, in those cases which are complex there is often evidence that the input of an Occupational Therapists in terms of environmental recommendation can be invaluable. |
| 1. 250 | ADASS | Quality statement 5 | Evidence that commissioners have an accommodation plan which maps potential housing needs over a (say) 5 year period, which includes a range of options. Such plans reduce the risk that support plans are delayed or restricted by the lack of availability of suitable accommodation |
| 1. 251 | Contact | Quality statement 5 | Contact agrees with the statement as a key area of quality improvement.  Appropriate housing is just one of the outcomes of the Preparing for Adulthood work, including as part of the SEND reforms. All work being done with children and young people should bear in mind the 4 themes of preparing for adulthood:  • Education and employment  • Health and Wellbeing  • Being part of the community, having friends and relationships  • Independent living and housing options |
| 1. 253 | Derbyshire County Council | Quality statement 5 | Can be measured through ASCOF returns |
| 1. 254 | Future Directions CIC | Quality statement 5 | Going forward Outcomes need more validated easy read research measures on quality of life such as the WHOQOL |
| 1. 255 | Future Directions CIC | Quality statement 5 | Equality & Diversity Section: as before should reference the RCSLT 5 Good Communication Standards here. Use of environmental and sensory assessments. Involvement of Occupational Therapists. The use of advocates to asses services. |
| 1. 256 | Future Directions CIC | Quality statement 5 | Shared ownership, private rent etc should be explored additional funding during transition clear time scales for individuals and better communication regular updates. |
| 1. 257 | Home From Home Care Limited | Quality statement 5 | The intention is the right one, but the standard fails to address and therefore take account of the impact of Registering the Right Support. There is some emerging evidence that Registering the Right Support is driving the local authorities to ask providers to deregister services and re-designate them as supported living environments. You need to capture this data as well. |
| 1. 258 | Lancashire Care NHS Foundation Trust | Quality statement 5 | Good principle but currently this is impacted by social care budget and/or range of specialist providers suitably skilled to support children and adults with LD and behaviour that challenges. In addition transforming care agenda encourages people to live in a geographical area based on commissioning (brining people back to commissioning authority area) rather than a choice of where the person may wish to live. |
| 1. 259 | Ludlow Street Healthcare | Quality statement 5 | It may be useful to prescribe a tool that supports assessment of need using a ‘threshold’ metric to evaluate where needs met are, optimal, adequate or inadequate as opposed to broad statement re ‘meeting needs’. Danger of services autonomously lowering threshold of ‘needs met’ if no formal metric is mandated. |
| 1. 260 | Mencap | Quality statement 5 | Rationale: is there anything that needs to be added about the focus on smaller community based placements being the preferred alternatives. The need for people to access and be a part of the communities they live in and to be participatory members of that community. This could link to CQC’s registering the right support guidance. There could also be something that stresses that both congregate settings and those that are “removed/separate” from the communities that people live can limit people’s ability to have a good QoL.  Evidence of housing specifications that have been developed in partnership with the individual and their families  Evidence of a range of housing options available as set out in the NHSE service model, including the option of a bespoke package.  Process a) data source: (use of term patients records, why is this not one of the criteria that the lead practitioner must include in their work).  Process b) data source - this is a difficult number to get and would involve an assessment of the environment as being fit for purpose for the supports that a person wants/needs. Link back to lead practitioner, but need a standardised tool that people are using so can compare numbers across families and social care provision.  What the Quality statement means: service providers (resources needs to include access to community development plans for new housing, like the training in communication with people with Learning disabilities as this is really important for those services that may be more generic (e.g. Housing supports).  Support to live where and how they want – it would be good to include reference to being an active member of their community (work, access to amenities) or the development of relationships. |
| 1. 267 | National Network of Parent Carer Forums (NNPCF) | Quality statement 5 | The NNPCF agree that this draft quality standard accurately reflects a key area for quality improvement.  Preparing for Adulthood from the earliest years is a key element of the SEND reforms. The SEND COP gives clear guidance to all professionals working with children and young people with SEND but in particular to those who work with young people aged 14 and over. This includes children and adult social care practitioners as well as health practitioners.  High aspirations for all is a key to success and all work being done with children and young people should bear in mind the 4 themes of preparing for adulthood:  • Education and employment  • Health and Wellbeing  • Being part of the community, having friends and relationships  • Independent living and housing options  These outcomes should be considered holistically, with the right focus on all elements to meet the personalised outcomes of each young person.  Families report a number of consistent issues across the country:  • Whilst there are often good, co-produced preparing for adulthood strategies and intentions, provision of services is lacking across the board.  • Joined up working across adult and children’s services is limited in many areas  • There is frequently poor planning that is not started soon enough  • Information about preparing for adulthood is limited and confusing both nationally and locally.  Families describe their young people approaching school leaving age as “the cliff edge”. Whilst at school, they understand the provision and support their young person is receiving and can align this with the outcomes for their young person. However, upon leaving school the offer from many, if not most local areas is less clear and very often families are unable to see how the services and provision available will serve to deliver the best possible outcomes for their young people with a learning disability, autism and behaviour that challenges. This is because information about services is often poor and too frequently, the services and support parents believe their young person needs are just not available  To achieve the Preparing for Adulthood outcomes of employment, independent living, community life and good health, approaches to joint commissioning need to engage not only the education, social care, health and public health sectors but also wider ‘whole system’ partners such as those concerned with employment and housing.  Parent expectations of CFA 2014 are high. Parents are aspirational for their children and young people who have a learning disability, autism and behaviour that challenges. Parents want better educational and life outcomes for this group of children and young people. |
| 1. 274 | NHS England | Quality statement 5 | Whilst this statement is appropriate it could be expanded to their other needs such as supported to find employment, maintain financial independence (independence to influence/manage their own social, financial and health needs). |
|  | Pennine Care NHS Foundation Trust | Quality statement 5 | We are pleased that this statement actively promotes Person Centred working |
|  | Pennine Care NHS Foundation Trust | Quality statement 5 | It is good to see housing is included as this can sometimes determine whether individuals can remain near home and vital support networks as opposed to moving to an out of borough placement |
| 1. 275 | Royal College of Occupational Therapists | Quality statement 5 | Housing – Occupational Therapists are key professionals who assess the housing needs of the person with Learning disability to enable them to be able to live as independently as possible. This should be reflected in this standard |
| 1. 276 | Royal College of Occupational Therapists | Quality statement 5 | The list of definitions should also include specific reference to equipment and adaptations required for housing needs for which assessment may be needed. |
| 1. 277 | Royal College of Paediatrics and Child Health | Quality statement 5 | Explanation of the statement clarifies its meaning but to state “how and where they want” is open to misinterpretation. GPs would not support homelessness or an illegal placement posing risk of abuse or where the person could abuse. The statement should be qualified in some way like “Subject to agreement” |
| 1. 278 | Royal College of Speech and Language Therapists | Quality statement 5 | It is good to see that a consideration for service providers is ensuring practitioners have training in how to communicate with service users. However we would recommend this specifies working with speech and language therapists who are the specialist professional needed to provide assessment and such training for this purpose. |
| 1. 279 | Royal College of Speech and Language Therapists | Quality statement 5 | We are uncertain why training practitioners in communication is first referenced in the section on housing (QS5). This must apply to all staff.  Up to 80% of people with learning disabilities have communication problems, with 50% having significant difficulties. It is essential that all practitioners understand speech, language and communication needs and how to respond to these and make adjustments to support people and their families.  It must therefore be a requirement that all practitioners receive training in communication and forms part of every QS. |
| 1. 280 | Surrey & Borders Partnership NHS Foundation Trust | Quality statement 5 | The Surrey & Borders Partnership NHS Foundation Trust has developed a multi-disciplinary Intensive Support Service (ISS) for people with learning disabilities. The ISS operates 7 days a week. The service is staffed every day from 8am till 8pm, with on-call arrangements in place overnight. All staff have experience of working with people who have learning disabilities and behaviours that challenge services. Additional training in Positive Behaviour Support and related topics are routinely provided within the service. The overall aim of the ISS is to prevent placement breakdown and avoid hospital admission, or reduce length of inpatient stay, in line with the Surrey Transforming Care Partnership Plan. The ISS was developed in order to provide timely and specialist assessment, advice, consultation and intervention in the community. Working alongside the East and West Surrey Community Teams for People with Learning Disabilities (CTPLDs), the ISS is able to provide an enhanced level of support to people deemed to be in the highest need.  Audit data from March – September 2018 indicated that hospital admissions had been prevented in 87% of cases and community placements had been maintained in 77% of cases. |
| 1. 281 | The British Psychological Society | Quality statement 5 | This section should reference exploring the compatibility of people with others in their housing in terms of choosing who they live with. The statement talks about ‘where and how’ people want to live but requires more reference to exploring with ‘who’ people want to live. To date, a lack of focus on this can result in people with a learning disability being housed with people they would not choose to or are not compatible with which can escalate behaviours that challenge.  This statement should indicate that people with learning disabilities should have the same choice as anyone else in the local community. There are a number of practicalities / restrictions (e.g. cost of accommodation, planning restrictions, size of accommodation and gardens, amount of parking etc.) that will have an impact on anyone’s choices about where and how to live, but people with learning disabilities should not have any less choice than others in the local community.  There is a lack of clarity in the Standard about when a person can move house. There needs to be more clarity about who has the power to say and what an individual can do to influence where they live. Too many people are trapped in abusive situations by the present rules and the decision needs to be person-centred.  The outcome does not seem to reflect the quality statement. The Statement seems to be ambitious in its remit regarding people with learning disabilities and behaviour that challenges being supported to live where and how they want; however the outcome being measured seems more realistic and measured. The outcome should reflect choices of where and how to live within the realistic options available and addressing responsibilities as tenants and citizens.  The Standard makes references to communication and sensory impairments but only recommends SALT input by those who would not necessarily be trained in sensory integration. It should include, where relevant and necessary, access to a qualified health professional trained in sensory assessment and sensory integration. |
| 1. 302 | Ludlow Street Healthcare | Other | 1.1 - Joint Commissioning. Idea of joint commissioning is a longstanding one however there remains very little operational guidance around how this can best be achieved and consequently it does not always work effectively and is frequently seen to hinder progression along care pathways from inpatient settings into community |
| 1. 303 | Ludlow Street Healthcare | Other | 1.2.7 – Reccs. Access to occupational therapy should also be highlighted alongside Speech and Language Therapy |
| 1. 304 | Ludlow Street Healthcare | Other | 1.2.22 – Medication. This section would benefit from reference being made to STOMP as a key strategy within LD services currently |
| 1. 305 | Ludlow Street Healthcare | Other | 1.4.2 – community services. Community services also need to develop capacity to be able to support discharge from inpatient services (as well as to prevent admission as already stated) |
| 1. 306 | Ludlow Street Healthcare | Other | 1.4.3. Also needs to include sensory and occupational therapy needs |
| 1. 307 | Ludlow Street Healthcare | Other | 1.4.9 – waiting times. Benchmarking around initial assessment waiting times would enable an agreed waiting time standard that services should strive to adhere to and avoid significant discrepancies across geographical footprints (in addition to those already stated for specialist support) |
| 1. 308 | Ludlow Street Healthcare | Other | 1.8.7 – contact during admission Nature of this contact should be specified in terms of frequency of telephone and face to face contact to ensure a minimum standard |
| 1. 309 | Ludlow Street Healthcare | Other | 1.8.9. Discharge plan should be a formal document with agreed specified goals that drive discharge planning. Nature with which 3 month review should be carried out needs to be clarified and the extent to which individuals are expected to be involved – i.e. active participation at attended meeting or individual review of discharge plan / MDT minutes |

## Registered stakeholders who submitted comments at consultation

2gether NHS Foundation Trust

ABA Access4All

ADASS

British Association of Social Workers

British Enhancement Centre (BEC)

Contact

Derbyshire County Council

Future Directions CIC

Home From Home Care Limited

Lancashire Care NHS Foundation Trust

Ludlow Street Healthcare

Mencap

National Network of Parent Carer Forums (NNPCF)

NHS England

NHS England (I)

Pennine Care NHS Foundation Trust

Royal College of General Practitioners

Royal College of Nursing

Royal College of Occupational Therapists

Royal College of Paediatrics and Child Health

Royal College of Psychiatrists

Royal College of Speech and Language Therapists

Salutem Healthcare

Surrey & Borders Partnership NHS Foundation Trust

Sussex Partnership Foundation Trust

The British Psychological Society

The Challenging Behaviour Foundation

Voyage Care

1. PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees. [↑](#footnote-ref-1)