NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

**Quality standard topic:** Service model for people with learning disabilities and behavior that challenges

**Output:** Prioritised quality improvement areas for development.

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for service model for people with learning disabilities and behaviour that challenges. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

* 1. Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development source referenced in this briefing paper is:

[Learning disabilities and behaviour that challenges: service design and delivery](https://www.nice.org.uk/guidance/ng93) (2018) NICE guideline NG93.

1. Overview
	1. Focus of quality standard

This quality standard will focus on the design, delivery and coordination of support and services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges, and their families and carers.

It will not cover:

* the prevention, assessment and management of mental health problems in people with learning disabilities
* interventions and support for children, young people and adults, with a learning disability and behaviour that challenges
* care and support of people growing older with learning disabilities.

These areas are covered by other published or referred quality standards.

* 1. Definition

**Learning disabilities**

A learning disability is defined by 3 core criteria:

* lower intellectual ability (usually an IQ of less than 70)
* significant impairment of social or adaptive functioning
* onset in childhood.

Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. The amount of everyday support a person with a learning disability needs will depend mostly on the severity of the disability. It is important to treat each person as an individual, with specific strengths and abilities as well as needs, and a broad and detailed assessment may be needed.

**Behaviour that challenges**

Some people with a learning disability display behaviour that challenges. The most commonly used definition of behaviour that challenges is: 'behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities' (Emerson et al. 1987).

'Behaviour that challenges' is not a diagnosis and is used in this quality standard to indicate that although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation or attracting attention). This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system.

* 1. Incidence and prevalence

An estimated 1.2 million children, young people and adults in England have a learning disability, and of these it is estimated that 10–17% display behaviour that challenges[[1]](#footnote-1). A more recent report suggested that there are over 40,000 children with learning disabilities who display behaviour that challenges[[2]](#footnote-2).

* 1. Management

The support needs of children, young people and adults with a learning disability were set out in 1992 in the Mansell report[[3]](#footnote-3), which identified the need to invest in developing local services with appropriate levels of skilled staff to meet people's needs. This was revised and restated in a later review, the so‑called 'Mansell 2 report'[[4]](#footnote-4), which also highlighted the increased use of placements away from people's homes.

The exposure of widespread abuse at Winterbourne View hospital in 2011 led to a review of care across England for people with a learning disability and behaviour that challenges. The resulting report Transforming care: a national response to Winterbourne View hospital[[5]](#footnote-5) started a programme of work to improve services. In particular, this aimed to shift emphasis from inpatient care in mental health hospitals towards care based on people's individual needs and wishes, provided by services in the community. The programme did not meet its original targets, as highlighted in a report by the National Audit Office[[6]](#footnote-6), and was reconfigured in 2015.

The 'transforming care programme' is now led jointly by NHS England, the Association of Directors of Adult Social Services, the Care Quality Commission, Local Government Association, Health Education England and the Department of Health. The national plan Building the right support[[7]](#footnote-7) included plans for 48 'transforming care partnerships' to pilot new arrangements of services. The national plan was followed by NHS England's national service model[[8]](#footnote-8) (October 2015) that set out the range of support that should be in place no later than March 2019.

1. Summary of suggestions
	1. Responses

In total 22 stakeholders responded to the 2-week engagement exercise 26/07/2018 - 23/08/2018.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 1 for further consideration by the Committee.

NHS Improvement’s patient safety division submitted a response during stakeholder engagement to say they did not have any comments. This can be found in appendix 3.

Full details of all the suggestions provided are given in appendix 3 for information.

Table 1 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders  |
| --- | --- |
| **Strategic planning and infrastructure*** Local leadership and joint commissioning
* Planning and delivering services according to local need
* Managing risk
* Quality assurance
 | * BASW, FPLD, HPFT, SCM 1, SCM 2
* NHSE, LGA and ADASS, PBS4, PF, SCM 3, SCM 4, SCM 5
* NHSE, LGA and ADASS, PA
* ABMUHB, CBF
 |
| **Enabling person-centred care and support*** Involving people and delivering support
* Coordinating care and support
* Care and support planning
 | * BASW, CBF, HPFT, MT, NHSE, LGA and ADASS, PA, PBS4, PF, RCPsych, RCSLT, SCM 4, SCM 6, TCS
* BASW, Mencap, MT, OLMG, PF, RCPCH, SCM 1, SCM 2, SCM 7
* BILD, Mencap, OLMG, PA, PF, SCM 7, TCS
 |
| **Early intervention and support for families and carers** | CBF, FPLD, HPFT, Mencap, PA, SfC, SCM 1, SCM 7, SCM 8, SCM 9, TCS |
| **Services in the community*** Developing services in the community
* Specialist behavioural support
 | * BILD, FPLD, NHSE, LGA and ADASS, RCPCH, RCPsych, SCM 6, SCM 2, SCM 9, TCS
* Mencap, PBS4, PF, SCM 9, SCM 1, SCM 3, SCM 6, SCM 5
 |
| **Housing** | ABMUHB, FPLD, HPFT, Mencap, MT, NHSE, LGA and ADASS, PF, SCM 2, SCM 4, SCM 7, SCM 8, TCS |
| **Short break services** | HPFT, TCS |
| **Inpatient Services** | OLMG, SCM5, SCM 7, SCM 8, SCM 9 |
| **Additional Areas*** Staff training
* Functional assessment and positive behavioural support
* Medication
* Identification of learning disabilities and terminology used
* Transition from children’s to adult services
 | * ABMUHB, BASW, BILD, CBF, FPLD, Mencap, OLMG, PBS4, RCPCH, RCPsych, SfC, SCM 1, SCM 4, SCM 5, SCM 6
* ABMUHB, MT, OLMG, PBS4
* RCPCH
* RCPCH
* OLMG, RCPsych, TCS
 |
| ABMUHB, Abertawe Bro Morgannwg University Health BoardBASW, British Association of Social WorkersBILD, British Institute of Learning DisabilitiesCBF, The Challenging Behaviour FoundationFPLD, Foundation for People with Learning DisabilitiesHPFT, Hertfordshire Partnership University NHS Foundation TrustMencapMT, Milestones TrustNHSE, LGA and ADASS - NHS England, Local Government Association and Association of Directors of Adult Social ServicesOLMG, OLM GroupPA, POhWER AdvocacyPBS4PF, People FirstRCPCH, Royal College of Paediatrics and Child HealthRCPsych, Royal College of PsychiatristsRCSLT, Royal College of Speech and Language TherapistsSfC, Skills for CareSCM, Specialist Committee MemberTCS, Three Cs Support |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1400 papers were identified for service models for people with learning disabilities and behaviour that challenges. In addition, 71 papers were suggested by stakeholders at topic engagement and 20 papers internally at project scoping.

Of these papers, 22 have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

1. Suggested improvement areas
	1. Strategic planning and infrastructure
		1. Summary of suggestions

### Local leadership and joint commissioning

Stakeholders highlighted the importance of having a lead commissioner with appropriate skills and experience to act on behalf of local authorities and clinical commissioning groups (CCGs) to commission support services in the community. Understanding local need and planning services that support people with behaviour that challenges from early on (a ‘whole life’ approach) were raised as key qualities for the lead commissioner. Stakeholders also felt that joined-up commissioning and pooled budgets between health, social care and education is a key way to simplify the system, ensure clarity about responsibilities, and improve the experience and outcomes of people with learning disabilities.

### Planning and delivering services according to local need

Stakeholders suggested that using local data, such as registers of people with learning disabilities, and planning services based on current and future need would help to prevent behaviours that challenge and the use of restrictive interventions. Planning services with people with learning disabilities and their families, and finding out about what services they need was raised as a key improvement area.

### Managing risk

Stakeholders felt that professionals jointly managing risk, and balancing keeping people safe with not being too risk averse, would prevent overuse of restrictive practices.

### Quality assurance

Stakeholders suggested indicators that can be used to identify whether services are providing good quality care or there are safeguarding issues, such as the use of restrictive practices, and felt that commissioners should specify service standards in contracts.

* + 1. Selected recommendations from development source

Table 2 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 2 to help inform the committee’s discussion.

Table 2 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Local leadership and joint commissioning  | **Local leadership**NICE NG93 Recommendations 1.1.1 and 1.1.2**Joint commissioning and funding**NICE NG93 Recommendation 1.1.3 |
| Planning and delivering services according to local need | **Planning and delivering services according to local need**NICE NG93 Recommendations 1.1.6 and 1.1.7 |
| Managing risk | **Managing risk**NICE NG93 Recommendation 1.1.9 |
| Quality assurance | **Quality assurance**NICE NG93 Recommendation 1.1.10 |

### Achieving change: strategic planning and infrastructure

### Local leadership – Recommendations for local authorities and clinical commissioning groups

NICE NG93 – Recommendation 1.1.1

Local authorities and clinical commissioning groups should jointly designate a [lead commissioner](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#lead-commissioner) to oversee strategic commissioning of health, social care and education services specifically for all [children](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#children), [young people](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#young-people) and [adults](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#adult) with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability), including those who display, or are at risk of developing, [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges).

NICE NG93 – Recommendation 1.1.2

Ensure that the lead commissioner:

* plans and oversees joined‑up commissioning arrangements
* has in‑depth knowledge and experience of working with children, young people and adults with a learning disability and behaviour that challenges, including knowledge of local services
* plans services that take a 'whole life' approach from early childhood onwards and enable smooth transitions.

### Joint commissioning and funding – Recommendations for the lead commissioners

NICE NG93 – Recommendation 1.1.3

The lead commissioner should ensure that budgets and other resources are pooled to develop local and regional services for children, young people and adults with a learning disability and behaviour that challenges. These should be pooled:

* across health, social care and education **and**
* with neighbouring authorities.

### Planning and delivering services according to local need – Recommendations for the lead commissioners

NICE NG93 – Recommendation 1.1.6

Ensure that service planning and delivery is based on an assessment of current and future service needs using:

* the local population prevalence of learning disabilities in children, young people and adults and the proportion who are likely to display behaviour that challenges
* an analysis of assessed needs in education, health and social care plans, to provide an early view of likely service needs and enable prevention and early intervention
* other sources of information, such as registers of people at risk of admission and other dynamic risk data; disabled children's registers; and records of referrals from liaison and diversion teams, youth offending teams and police.

NICE NG93 – Recommendation 1.1.7

Ensure that services are planned and delivered in a way that:

* is co‑produced with children, young people and adults using services and their families, carers and independent advocates
* enables person-centred planning and provision
* addresses the needs of different age groups but also takes a 'whole life' approach to planning
* includes planning for a range of future housing and employment support needs
* integrates health, social care and other relevant services.

### Managing risk – Recommendation for local authorities and clinical commissioning groups

NICE NG93 – Recommendation 1.1.9

Take joint responsibility with service providers and other organisations for managing risk when developing and delivering care and support for children, young people and adults with a learning disability and behaviour that challenges. Aim to manage risks and difficulties without resorting to changing placements or putting greater restrictions on the person.

### Quality assurance – Recommendations for commissioners and service providers

NICE NG93 – Recommendation 1.1.10

Ensure services meet set service-level and individual outcomes, and that service providers show evidence of achieving these outcomes. This evidence could include:

* satisfaction and quality-of-life ratings of children, young people and adults who have used the service, and their family members, friends and carers
* outcomes measured by personalised and validated tools such as the 'measure of processes of care' (MPOC) tool, or the 'patient feedback questionnaire' (PFQ)
* a reduction in duration and frequency of behaviour that challenges
* stability of placements
* participation in education by children and young people
* reports on the use of restrictive interventions, including medication
* contact time with specialist professionals
* evidence from quality reviews and spot checking involving [experts by experience](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#experts-by-experience)
* quality checks by user-led organisations.
	+ 1. Current UK practice

### Local leadership and joint commissioning

Dame Christine Lenehan’s review[[9]](#footnote-9) into issues with care for children with complex needs and behaviour that challenges drew evidence from civil servants, clinicians, managers, parents and young people. She found that issues about effective commissioning ran through the review and commissioners (specialised commissioners and CCGs) highlighted the following:

* the service model for children is not well known or understood
* poor levels of awareness of this group of children in services
* difficult to see an effective commissioning process in practice
* you can’t commission a service if there is no suitable service to commission
* there was little evidence of systematic cross-system commissioning with health and local authorities of good early intervention and therapeutic family support/short breaks services
* confusion about what was expected of them and what the minimum expectations are

it is clear that resources have to deliver the mandated Government priorities, other commissioning is at their discretion and should be based on population needs.

Issues were also found with joint working across agencies:

* fragmentation across the 3 statutory agencies created a lack of ownership
* issues with managing cultures and working arrangements to enable a co-ordinated approach
* no one place for support and oversight, and no single point of accountability within the NHS or wider system, either at national or local levels
* in many areas each agency believed that the other should be more engaged, more proactive, more responsible
* both managers and clinicians believed that they had responsibility but there was no collective ownership. It was rare for agencies to see these children as their collective responsibility

interviewees talked about a lack of mutual respect between education and Children and Young People's Mental Health Services, and a lack of clarity in terms of who does what.

The Royal College of Nursing (RCN) published a report[[10]](#footnote-10) on frontline learning disability services, based on surveys of 1,100 learning disability nurses from across the UK, including 771 nurses in England, and in-depth interviews with nurses whose jobs have been transferred outside the NHS. The report found that:

* 40% had seen evidence of integration in their area, with only 25% saying they had not
* 35% said they neither agreed nor disagreed that there was evidence of integration in their area
* 28% said that lack of integration was one of the key barriers to improving care for those with learning disabilities.

NHS England commissioned a report[[11]](#footnote-11) to make recommendations to transform the commissioning of services for people with learning disabilities and/or autism following the Winterbourne View scandal. Sir Stephen Bubb, chief executive of charity leaders body the Association of Chief Executives of Voluntary Organisations, and a steering group of representatives from the voluntary sector, the NHS and local government, individuals with learning disabilities and/or autism, and family members, engaged with a range of stakeholders to produce the report. The findings include:

* many local commissioners (in local councils and clinical commissioning groups) were enthusiastic about making the shift towards joint commissioning and pooled budgets happen, but many local commissioners and areas did not have this in place
* commissioners, providers and families cited disputes over who should fund what as a reason for inappropriate placements, and the growing number of people in inpatient settings suggested that in many areas, what local plans were drawn up did not meet the scale of the challenge
* common causes for the above issues included:
	+ lack of local leadership, and weak accountability. Where local commissioners had been successful in expanding community-based provision and reducing the need for inpatient beds, active senior leadership backing was often cited as key to their success. But where that leadership was lacking, the national organisations and people with learning disabilities and/or autism or their families did not seem to be able to hold local commissioners to account
	+ insufficient support, assurance and challenge. Commissioning services for people with such complex needs is a highly-skilled job, but commissioning capacity has reduced in many areas, which is a significant obstacle to progress.

The National Audit Office audit of care services for people with learning disabilities and behaviour that challenges[[12]](#footnote-12) examined whether the government had met its objectives set out in the Winterbourne View Concordat. They reviewed Learning Disabilities Programme Board’s self-assessment returns showing progress against each of the commitments, analysed data collected quarterly under ‘Assuring Transformation’, from December 2013 to September 2014, reviewed patient case files in 4 large mental health hospitals, interviewed officials in audited bodies and conducted a literature review. They found that the government did not achieve the main goal set in the Concordat to move all people, where appropriate, out of hospitals by 1st June 2014 because no mechanisms existed for the systematic pooling of resources to build sufficient capacity in the community to enable it to happen. As of June 2013 only 27% of local areas reported a pooled or aligned health and social care budget.

### Planning and delivering services according to local need

The CQC findings from inspections of specialist mental health services in England from 2014 to 2017[[13]](#footnote-13) found that the better services also involved people with a learning disability in reviewing and advising on improvements to the service and in the process for recruiting new staff.

### Managing risk

No current practice information identified.

### Quality assurance

Public Health England’s statistics on people with learning disabilities and the services and support available to them and their families[[14]](#footnote-14) reported that in 2014/15 safeguarding referrals (where a concern is raised with a council about a risk of abuse, which instigates an investigation under the local safeguarding procedures) were made for 15,715 people with learning disabilities, with a consistent decrease from 2011/12 to 2014/15.

The Care Quality Commission (CQC) findings from inspections of specialist mental health services in England from 2014 to 2017[[15]](#footnote-15) included examples of where staff had taken action that resulted in a marked reduction in the use of physical restraint and seclusion. However, they were concerned about the high use of restrictive interventions in some inpatient services.

The RCN report[[16]](#footnote-16) on frontline learning disability services found that learning disability nurses identified an improvement in greater safeguarding measures and nursing input into the process.

* + 1. Resource impact

None of the recommendations were identified as having a significantresource impact(>£1m in England each year).

* 1. Enabling person-centred care and support
		1. Summary of suggestions

### Involving people and delivering support

Stakeholders highlighted that support for people with learning disabilities should be person-centred and based on their needs and choices. The importance of considering communication needs to enable the involvement of people with learning disabilities, and prevent behaviour that challenges, was raised. Stakeholders suggested ways to support communication, such as easy read information, story boards and assistive technology. Identifying difficulties with swallowing was also raised as a way to prevent behaviour that challenges. Stakeholders felt that support should allow independence, meaningful activity, opportunities for establishing and maintaining relationships and having social interactions. People need to know what services are available, and have access to services to support health and wellbeing, such as employment opportunities and healthcare services.

### Coordinating care and support

The importance of a person with learning disabilities’ support network, including family, friends, carers and professionals, working in partnership was raised by stakeholders. Stakeholders felt that having a named individual to coordinate support, and build relationships, both with the individual and with people in their support network, was key to improving outcomes by ensuring consistency and stability for the person with learning disabilities. Shared learning and joint working between different teams was also felt to have benefits.

### Care and support planning

Stakeholders highlighted how involving the person with learning disabilities, their family, carers and support workers in planning their support will make sure that the person feels more in control and has a better quality of life, so behaviour that challenges is less likely. Stakeholders felt there should be clarity around who is responsible for leading on assessments and developing support plans. Regular reviews of assessments and support plans, and ensuring consistency and managing change were also considered important areas.

* + 1. Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 3 to help inform the committee’s discussion.

Table 3 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area  | Selected source guidance recommendations |
| Involving people | **Involving people with a learning disability and behaviour that challenges** NICE NG93 Recommendations 1.2.1 to 1.2.5, and 1.2.7**Delivering care and support**NICE NG93 Recommendations 1.2.21 and 1.2.23 |
| Coordinating care and support | **Coordinating care and support**NICE NG93 Recommendations 1.2.10 to 1.2.13 |
| Care and support planning | **Care and support planning**NICE NG93 Recommendations 1.2.14, 1.2.16 to 1.2.18 |

**Enabling person-centred care and support**

**Involving people with a learning disability and behaviour that challenges – Recommendations for practitioners working with children, young people and adults, and their families and carers**

NICE NG93 – Recommendation 1.2.1

Practitioners working with children, young people and adults with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability) and [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges), and their family members and carers, should get to know the person they support and find out what they want from their lives, not just what they want from services.

NICE NG93 – Recommendation 1.2.2

Actively involve people with a learning disability in all decisions that affect them. If a person aged 16 or over lacks the capacity to make a decision, staff must follow the [Mental Capacity Act 2005](http://www.legislation.gov.uk/ukpga/2005/9/contents).

NICE NG93 – Recommendation 1.2.3

Assess whether a child or young person under the age of 16 is [Gillick competent](https://www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition) and work in partnership with all children and young people. Include them in decisions about their treatment and ask them how they would like their families or carers to be involved.

NICE NG93 – Recommendation 1.2.4

Involve families, friends, carers or independent advocates if this is what the person wants, or where decisions are made in the best interests of a person aged over 16 in line with the [Mental Capacity Act 2005](http://www.legislation.gov.uk/ukpga/2005/9/contents). This should be done unless there is a compelling reason not to (for example, if there are safeguarding concerns).

NICE NG93 – Recommendation 1.2.5

Support children, young people and adults with a learning disability and behaviour that challenges to live where and how they want. Give them support that:

* is person-centred, reflecting their individual needs and choices, and maximising their control
* helps them take an active part in all aspects of daily life that they choose, based both on what they can do and what they want to do
* takes into account the severity of their learning disability; their developmental stage; any communication difficulties or physical or mental health problems; and their life history
* respects their cultural, religious and sexual identity
* helps them before problems occur or as soon as they emerge, not just when crisis has been reached
* encourages people to speak out if they have any worries
* promotes continuity of relationships.

**Involving people with a learning disability and behaviour that challenges – Recommendation for commissioners and practitioners working with children, young people and adults**

NICE NG93 – Recommendation 1.2.7

Ensure that people with a learning disability and behaviour that challenges have access to speech and language therapy when they need it.

**Delivering care and support – Recommendations for staff in all settings**

NICE NG93 – Recommendation 1.2.21

In all settings, staff working with children, young people and adults with a learning disability, and their families and carers, should aim to reduce the risk of behaviour that challenges developing by:

* identifying health or sensory problems early
* providing strategies and interventions to support communication.

Follow recommendations on [psychological and environmental interventions](https://www.nice.org.uk/guidance/ng11/chapter/1-Recommendations#psychological-and-environmental-interventions-2) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

NICE NG93 – Recommendation 1.2.23

Ensure that children, young people and adults with a learning disability and behaviour that challenges know about and are able to use services to support their health and wellbeing. These should include:

* services helping people to make and maintain friends, relationships and social networks in their community and take part in community activities
* access to employment and pre-employment opportunities
* day opportunities where activities can be tailored to the person's interests, preferences, strengths and abilities
* universal healthcare services and health checks
* peer support opportunities.

**Coordinating care and support – Recommendations for local authorities, clinical commissioning groups and service providers**

NICE NG93 – Recommendation 1.2.10

Local authorities working in partnership with healthcare professionals should assign a single practitioner, for example, a social worker (in a disabled children's team or community learning disability team) or community psychiatric nurse, to be the person's 'named worker'. The named worker should get to know the person and coordinate support to meet their needs over the long term.

NICE NG93 – Recommendation 1.2.11

The local authority, clinical commissioning group and [service providers](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#service-providers) should liaise regularly with the named worker, keeping them informed and involved in decision-making.

**Coordinating care and support – Recommendations for the named worker**

NICE NG93 – Recommendation 1.2.12

Arrange regular meetings to discuss the person's care and support, and invite people in their support network, including family members, carers, independent advocates and practitioners from all services that support them. This could build on existing processes, for example, the education, health and care planning and review process for children (see Gov.uk's [children with special educational needs and disabilities](https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help)).

NICE NG93 – Recommendation 1.2.13

Recognise and use the expertise brought by all members of the person's support network (not only those who are paid).

**Care and support planning – Recommendations for community learning disability teams and service providers**

NICE NG93 – Recommendation 1.2.14

Community learning disability teams (or relevant children's services, for example, disabled children's teams) and service providers should work in partnership with the child, young person or adult, their family members, carers and independent advocates and their named worker to develop, deliver and review their care and support plan. Develop a care plan that:

* meets the person's needs and preferences
* works to support and maximise the person's mental capacity
* takes into account people's fluctuating mental capacity and needs
* adopts a 'whole life' approach that covers what they want to achieve in both the short and long term, and supports smooth transitions
* takes a positive approach to managing risk
* sets out what to do to prevent or respond to a crisis.

NICE NG93 – Recommendation 1.2.16

Community learning disability teams or relevant children's services (for example, disabled children's teams) and service providers should review children, young people and adults' care and support with their named worker:

* according to timings agreed in their plan**and**
* whenever there is a significant change, for example, if the person is placed out of area.

NICE NG93 – Recommendation 1.2.17

When reviewing plans:

* involve people as set out in [recommendations 1.2.1 to 1.2.4](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#recommendations-for-practitioners-working-with-children-young-people-and-adults-and-their-families)
* take account of people's fluctuating mental capacity
* check that staff are following the [behaviour support plan](https://www.nice.org.uk/guidance/ng11/chapter/recommendations#behaviour-support-plan) recommendations in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
* think about plans for the future, including whether changes might be needed to the person's housing or support.

NICE NG93 – Recommendation 1.2.18

As soon as a child, young person or adult develops behaviour that challenges, community learning disability teams (or relevant children's services, for example, child and adolescent mental health learning disability teams) and service providers should offer to work with them and their family or carers to develop a behaviour support plan.

For more information on what this should include, see the recommendations on [behaviour support plan](https://www.nice.org.uk/guidance/ng11/chapter/recommendations#behaviour-support-plan) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions.

* + 1. Current UK practice

### Involving people

The Department of Health and Social Care’s consultation on how to strengthen the rights of people with learning disabilities, autism and mental health issues[[17]](#footnote-17) received 481 responses from 468 different individuals, groups or organisations. Responses were received from across England. Half of the 198 responses from individuals (54%) stated that the person providing feedback had either a mental or physical health issue, or disability. The main groups who responded were the voluntary sector (54%) including larger national and smaller more regional organisations, local authorities (18%) and NHS organisations (12%).

Respondents were clear that whilst many rights do exist for example Human Rights Act 1998, Mental Health Act 1983 and Equality Act 2010, Care Act 2014 and the Children and Families Act 2014, these are not universally understood and individuals are not supported and enabled to exercise these effectively. This often resulted in people not receiving good quality care and support in line with their wishes and needs.

The consultation also had feedback that there was already much good work in progress to meet the new accessible Information Standard.

The RCN report[[18]](#footnote-18) on frontline learning disability services found that learning disability nurses identified some specific improvements in services:

* more robust CQC inspections and monitoring use of the Mental Health Act
* a shift towards a more patient-centred approach to deliver better-quality care
* shared and more in-depth care planning

increased transparency, with service users being more involved in decision making.

NHS England’s report recommending how to transform the commissioning of services for people with learning disabilities and/or autism[[19]](#footnote-19) heard from stakeholders that they often feel powerless and their rights are unclear, misunderstood or ignored. In some cases, people with learning disabilities and/or autism and their families may not be aware of the rights they already have, or may not have access to the support they need to exercise those rights (such as access at the right time to an advocate or lawyer – for instance, during a crisis, at point of admission, or when in an inpatient setting).

However it reported that many frontline staff do think more often of people as people and citizens with rights (not just patients with problems), to engage individuals or their families in care more and to be aspirational about what people can achieve.

The CQC findings from inspections of specialist mental health services in England from 2014 to 2017[[20]](#footnote-20) also found:

* the majority of staff they encountered showed caring, considerate and compassionate interactions with people with a learning disability or autism using their services
* staff were frequently mentioned as “recognising (the) individual needs” of patients and ensuring other providers were aware of them. Most services were generally taking the communication needs of patients into account. For example, one service had developed a core team of staff trained in British Sign Language and Makaton to work with the patients. This appeared to have worked well, as incidents had reduced due to enabling patients’ communication with staff.
* positive examples of documents, leaflets and reports commonly being available in easy read format. In most cases, staff were providing information, support and encouragement for people, their families and carers on how to make complaints.
* one area of improvement for some services was to address the lack of information on wards about Independent Mental Health Act advocacy and supporting patients to make contact with an advocate.

The Learning Disabilities Mortality Review Programme carried out 22 case reviews of deaths and serious incidents involving people with learning disabilities from across England in 2015-2017. Some of their key findings[[21]](#footnote-21) around the Mental Capacity Act 2005 include:

* under-use of assessment of capacity
* not employing an independent advocate
* a lack of understanding of the Act by practitioners.

NHS Digital data on measures from the Adult Social Care Outcomes Framework, England - 2017-18[[22]](#footnote-22) reports that:

* the proportion of adults with learning disabilities in paid employment is 6%. This has increased from 5.7% in 2016-17
* the proportion of adults with a learning disability in paid employment varies across each region in England. London (7.5%) and Eastern (7.5%) have the highest proportion, North West, East Midlands and West Midlands have the lowest proportion of adults with a learning disability in paid employment at 4.3%.

### Coordinating care and support

The RCN report[[23]](#footnote-23) on frontline learning disability services reported that freedom of information requests from Mencap in November 2014 showed that 42% of 165 NHS acute trusts did not have a Learning Disability Liaison Nurse. Mencap also found that on average, each trust only had 30 hours of learning disability nursing cover out of 168 hours in the week. The RCN survey supports these findings, with 50% of nurses saying their employer did not have an acute Learning Disability Liaison Nurse.

The CQC inspections of specialist mental health services[[24]](#footnote-24) found that many learning disability and autism services worked well with other health and social services to build partnerships to meet the needs of patients and carers. There was also evidence of services working with other agencies such as local authorities, police, schools and housing associations to support patients.

The Learning Disabilities Mortality Review Programme key findings[[25]](#footnote-25) around issues with interagency communication and working include:

* a lack of multi-agency communication and planning, specifically around weight, behaviour, and transition from child to adult services
* poor communication between organisations about health and care needs
* a lack of communication about concerns over risk, leading to safeguarding issues.

### Care and support planning

Pathways Associates were asked by NHS England to gather feedback on how well the care and treatment review[[26]](#footnote-26) (CTR) policy was working for people with a learning disability, autism or both[[27]](#footnote-27). The report contains feedback from families and people with a learning disability and/or Autism who had a review, along with experts by experience and clinical experts. It focuses primarily on the northwest of England, but they tried to secure the views of people in other regions of the country.

Out of the 25 people who answered a question on whether they thought people were listening to their views in the CTRs, 96% answered ‘yes’ and 4% answered ‘no’.

The CQC inspections of specialist mental health services[[28]](#footnote-28) found that:

* some services needed to improve the quality and consistency of care planning in both ward-based and community-based services. Although some plans were holistic and staff updated them according to changing needs, others were lacking detail or not personalised and, in some cases, not all staff could access them

most services involved people in their own care planning – giving people time to voice their views and influence their care. Staff in some services encouraged patients to rate their own risk by using a red, amber or green rating scale. This showed that staff valued and respected patients' self-assessment.

The Learning Disabilities Mortality Review Programme key findings[[29]](#footnote-29) included issues with professional practice, including:

* failure to follow good practice or made poor decisions. This was usually due to insufficient or ineffective use of assessment and care plans, health action plans, and hospital passports
* underuse of historical information to inform decision-making

poor record keeping by care staff.

A system issue was also identified with care plans that were ineffective, unsubstantial, or not reviewed on a regular basis.

* + 1. Resource impact

None of the recommendations were identified as having a significantresource impact(>£1m in England each year).

* 1. Early intervention and support for families and carers
		1. Summary of suggestions

Stakeholders highlighted the importance of giving the families of people with learning disabilities the support and information they need, including what to do in an emergency, how to make a complaint and how to access services, early on. It was felt that this would increase the confidence and skills of families, so that there is less reliance upon services, people with learning disabilities can stay within family environments and the use of behaviour that challenges is reduced. Training for families was also suggested as a way of helping with this.

* + 1. Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee’s discussion.

Table 4 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Early intervention and support for families and carers | **Early intervention and support for families and carers**NICE NG93 Recommendations 1.3.1 to 1.3.6 |

### Early intervention and support for families and carers – Recommendations for local authorities

NICE NG93 – Recommendation 1.3.1

Ensure that families and carers of children, young people and adults with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability) and [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges) are given support that helps them to:

* manage their role as carers
* care for the person and meet their needs, in relation to behaviour, care and support, communication, physical health, mental health, educational needs or any offending behaviour
* access support from specialist services when needed.

NICE NG93 – Recommendation 1.3.2

Provide information, guidance and ongoing support for families and carers of children, young people and adults with a learning disability and behaviour that challenges, which address different aspects of their life. Sources of support could include:

* peer support
* parent and carer groups or forums
* email support
* individual phone and face-to-face support
* family networks
* independent advocacy
* managed email networks (a shared discussion forum)
* social media groups.

NICE NG93 – Recommendation 1.3.3

Give family members and carers information in line with [support and interventions for family members or carers](https://www.nice.org.uk/guidance/ng11/chapter/1-Recommendations#support-and-interventions-for-family-members-or-carers-2) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions. This could be in the form of a 'welcome pack'. Provide this information:

* at the first point of contact with families
* through the local authority website, local libraries and universal services such as GP surgeries.

**Early intervention and support for families and carers – Recommendations for the named worker**

NICE NG93 – Recommendation 1.3.4

Help people and their families to understand information about available support (see recommendation 1.3.3) from first contact onwards.

NICE NG93 – Recommendation 1.3.5

Advise family members and carers how to access:

* [short break](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#short-breaks) services
* specialist behaviour support
* training as set out in [recommendations 1.7.1 and 1.7.2](https://www.nice.org.uk/guidance/ng11/chapter/1-Recommendations#psychological-and-environmental-interventions-2) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
* support in an emergency
* community resources, including voluntary organisations, networks and support groups
* local safeguarding procedures, including how to raise safeguarding concerns or make a complaint.

NICE NG93 – Recommendation 1.3.6

Ensure that family members and carers have information such as contact details of staff and key dates and appointments.

* + 1. Current UK practice

Dame Christine Lenehan’s review[[30]](#footnote-30) found that lack of communication and support for parents was a key issue raised in the individual case reviews of the young people that prompted the review.

Public Health England’s statistics on people with learning disabilities and the services and support available to them and their families[[31]](#footnote-31) reported that:

* over two fifths of family carers of people with learning disabilities felt it was very/fairly easy to find information/advice (42.0%), 28.4% found it difficult and 29.5% had not tried to find information/advice in the past 12 months
* 58.0% of family carers reported that the information/advice they had received was very/quite helpful, 1 in 10 carers found it to be quite/very unhelpful and 30.9% did not receive any information/advice in the last 12 months.
* family carers were also asked if they felt involved/consulted in discussions about the support of the person they were caring for. 32.5% reported always being involved/consulted; 43.3% usually/sometimes involved/consulted; and 5.4% reported never being involved/consulted. 18.4% reported that there hadn’t been any discussions they were aware of
* overall, family carers of adults with learning disabilities reported slightly lower levels of satisfaction with the support received than other family carers, in terms of being: extremely/very satisfied (38% vs 41%), quite satisfied (34% vs 33%), neither satisfied nor dissatisfied (14% vs 15%), or quite/very/extremely dissatisfied (17% vs 11%)
* from 2007/08 to 2014/15, there has been a reduction in the number of family carers of an adult with learning disabilities getting a service for themselves as carers, with the number of family carers getting information/advice/signposting plateauing from 2010/11
* 14,375 family carers were getting support in the form of information/advice/signposting or a universal service only
* 10,265 family carers were getting no direct support
* in terms of specific services, cared for adults with learning disabilities were more likely than cared for adults overall to have used: a day centre (65% vs 30%), a short break for 24 hours or more (41% vs 22%), a short break for less than 24 hours (33% vs 25%), an emergency short break service (19% vs 16%) and a personal assistant (32% vs 15%).
* in terms of support for themselves as family carers of people with learning disabilities in the previous 12 months:
	+ almost half reported receiving information or advice (46.2% vs 53.9% of family carers generally)
	+ over a quarter reported accessing carers’ groups (26.8% vs 30.8% generally)
	+ very few reported receiving carer training (5.0% vs 5.5% generally)
	+ very few reported receiving support to stay in employment (4.7% vs 3.4% generally)
* in 2013/14, 38,755 assessments/reviews were offered to family carers of adults with learning disabilities aged 18 to 64 years, of which 93% were taken up. This represents 74% of households where an adult with learning disabilities aged 18 to 64 years was reported to be in settled accommodation with family or friends. For family carers of adults with learning disabilities aged 65 years or more, 3,000 assessments/reviews were offered, of which 95% were taken up.
* in 2014/15, in total 56,220 of 128,356 family carers responded to the Personal Social Services Survey of Adult Carers in England (a 43.8% response rate). For 6,160 (11.0%) of these family carers the primary support need of the cared for person was a learning disability. 30.2% were not in paid employment because of their caring responsibilities, compared with 20.5% for all carers in England.

The Learning Disabilities Mortality Review Programme key findings[[32]](#footnote-32) around issues with communication with families, carers and people with learning disabilities include:

* practitioners not communicating with family or representatives about the care needs of people with disabilities
* staff and professionals unclear of the need to involve or inform family members
* ineffectual support for parents with learning disabilities
* the need to understand complexities presented by culture and diversity when working with families.
	+ 1. Resource impact

None of the recommendations were identified as having a significantresource impact(>£1m in England each year).

* 1. Services in the community
		1. Summary of suggestions

### Developing services in the community

Stakeholders highlighted that people with learning disabilities should have access to health and social care services in the community to support their physical and mental health needs, and prevent behaviour that challenges and inpatient admissions. Stakeholders stated that access to mainstream services and health and wellbeing outcomes should be equitable, but felt that people with learning disabilities experience inequalities. Access to child and adolescent mental health service (CAMHS) practitioners in the community with experience of learning disabilities was specifically raised. Having local services and community-based support was felt to be important to enable people to stay in their communities and near their families, in particular for children and young people.

### Specialist behavioural support

Stakeholders suggested that specialist behavioural support teams should be available in the community to enable early intervention and prevent admissions to hospital and secure settings, to support discharge from secure settings, and give improved outcomes. Having this support available during a crisis was felt to be important. Creating community forensic teams for people with learning disabilities was also raised.

* + 1. Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee’s discussion.

Table 5 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Developing services in the community | **Developing services in the community** NICE NG93 Recommendations 1.4.1 to 1.4.6, 1.6.2 and 1.6.3 |
| Specialist behavioural support | **Specialist behavioural support** NICE NG93 Recommendations 1.4.7 to 1.4.9**Intensive behavioural support during a crisis**NICE NG93 Recommendations 1.4.10 and 1.4.11**Services for people in contact with, or at risk of contact with, the criminal justice system**NICE NG93 Recommendation 1.4.12 |

### Services in the community – prevention, early intervention and response

### Developing services in the community –Recommendations for the lead commissioner

NICE NG93 – Recommendation 1.4.1

The [lead commissioner](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#lead-commissioner) should commission services in the community for people with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability) and [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges) (including for people in contact with, or at risk of contact with, the criminal justice system). These services:

* should be able to cater for lower-level needs up to intensive, complex or fluctuating needs
* could be set up either as 1 large team with different subteams or as several separate teams
* should be provided wherever possible as an alternative to, and to reduce the potential need for:
	+ inpatient care for children, young people and adults **or**
	+ [residential placements](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#residential-placement) for children and young people.

NICE NG93 – Recommendation 1.4.2

Services in the community should fulfil the following core functions:

* specialist prevention and early intervention
* developing capacity in non-specialist community services to prevent unnecessary inpatient admissions
* giving support and training to families and carers (by following the recommendations on [support and interventions for family members or carers](https://www.nice.org.uk/guidance/ng11/chapter/1-Recommendations#support-and-interventions-for-family-members-or-carers-2) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
* quality assurance and service development
* short-term assessment and intervention
* longer-term complex intervention
* crisis response and intervention.

NICE NG93 – Recommendation 1.4.3

Ensure that children, young people and adults with a learning disability can get specialist support through their community learning disability team that meets their needs, for example, in relation to:

* behaviour
* communication
* social care and support needs
* physical health
* mental health
* education
* offending behaviour.

This could be achieved by employing relevant practitioners within the community learning disability team or by developing close links with practitioners in other relevant services.

### Developing services in the community – Recommendations for community learning disability teams and service providers

NICE NG93 – Recommendation 1.4.4

Services who provide support through the community learning disability team should work together and provide consultancy and support to each other. They should work with children, young people and adults, and their family members and carers, in a way that is:

* personalised
* flexible
* responsive
* accessible
* reflective.

NICE NG93 – Recommendation 1.4.5

If a child, young person or adult develops, or is at risk of developing, offending behaviour, community learning disability teams should refer them to appropriate specialists, such as community [forensic](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#forensic-services) or youth justice services, as soon as possible (see [recommendations 1.4.12 to 1.4.16](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#services-for-people-in-contact-with-or-at-risk-of-contact-with-the-criminal-justice-system)). These services should:

* provide evidence-based early interventions that are adapted for people with a learning disability and address the specific behaviour
* work in an ongoing partnership with each other and with the community learning disability team whenever needed.

NICE NG93 – Recommendation 1.4.6

Community learning disability teams should maintain good communication and links with the police and liaison and diversion teams so that:

* they can advise on assessments of vulnerability, particularly for people with mild or borderline learning disabilities who may otherwise not be identified as vulnerable
* people who need support can be diverted from the criminal justice service to community learning disability teams.

### Services for children and young people – Recommendations for local authorities, clinical commissioning groups and the lead commissioner

NICE NG93 – Recommendation 1.6.2

Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with [section 17](http://www.legislation.gov.uk/ukpga/1989/41/section/17) of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to [residential placements](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#residential-placement) away from home and to reduce the potential need for such placements.

NICE NG93 – Recommendation 1.6.3

The [lead commissioner](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#lead-commissioner) should ensure that specialist behavioural support in the community for children and young people includes support from education and child and adolescent mental health service (CAMHS) practitioners who have skills and experience in working with children and young people with a learning disability and behaviour that challenges.

### Specialist behavioural support – Recommendations for the lead commissioner

NICE NG93 – Recommendation 1.4.7

Ensure that specialist assessment and behavioural support are available in the community so that children, young people and adults can stay where they currently live and avoid moving.

NICE NG93 – Recommendation 1.4.8

Ensure that specialist services for behaviour that challenges are available to everyone with a learning disability and behaviour that challenges, based on an assessment of each person's need and risk and taking into account the benefit of early intervention.

NICE NG93 – Recommendation 1.4.9

The lead commissioner should:

* set local maximum waiting times for initial assessment, and for urgent and routine access to treatment and support
* ensure that waiting times for specialist behavioural support do not exceed NHS waiting time standards.

**Intensive behavioural support during a crisis – Recommendations for local authorities, clinical commissioning groups, community learning disability teams and specialist services**

NICE NG93 – Recommendation 1.4.10

Provide a local, personalised response to children, young people and adults who need intensive support during a crisis. This response should:

* focus on keeping people in their own home
* have an out-of-hours helpline as a first option with the capacity to respond rapidly (within 1 hour or in line with local mental health crisis response times), staffed by people with skills and knowledge in learning disabilities and behaviour that challenges, and specialist skills in mental health problems
* provide face-to-face support within 4 hours if needed, based on initial triage
* involve partnership with other commissioners, [service providers](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#service-providers) and family members and carers
* include giving staff access to the person's information if they are already in contact with services
* provide short-term support to achieve aims that are agreed with the person
* include clear contact details for children's services (as set out in the Local Offer) and adults' services.

NICE NG93 – Recommendation 1.4.11

Use a clear, coordinated approach to reducing the level of support from more intensive services in line with the person's needs. Learn from what happened and use this knowledge to inform future early intervention and prevention services and support crisis plans.

**Services for people in contact with, or at risk of contact with, the criminal justice system – Recommendation for local authorities and clinical commissioning groups**

NICE NG93 – Recommendation 1.4.12

Commission local community [forensic services](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#forensic-services) for children, young people and adults with a learning disability and behaviour that challenges who are in contact with, or at risk of contact with, the criminal justice system to prevent out-of-area hospital placement. These could be provided as stand-alone teams, or as a specialism within an existing team, for example, a community learning disability team, or a learning disability specialism within a community forensic team.

* + 1. Current UK practice

### Developing services in the community

The Department of Health and Social Care’s consultation[[33]](#footnote-33) reported that two thirds of responses said that responsibilities of organisations and of individuals to ensure that an individual’s physical and mental health care needs are fully considered and supported, wherever they are located, should be clearer.

The consultation also asked questions about supporting people to live independently, at home or in the community, rather than in inpatient settings. Concerns were raised about the community services available to support this, both in terms of what was available and its quality. Respondents were clear that one of the most significant challenges to supporting people to live in the community was the lack of available community services in some areas.

The RCN report[[34]](#footnote-34) on frontline learning disability services found that:

* 52% of nurses surveyed disagreed with the statement that people with learning disabilities can access the right care in the right place when they need it
* 85% of learning disability nurses say there are not enough of the right services in the community to support and care for people
* only 22% of learning disability nurses agreed with the statement that there are now better services in the community than there were three years ago; 47% disagreed or strongly disagreed
* improvements in services identified by learning disability nurses included that some patients had been moved closer to home, there were more placements in community settings, and there is better access to primary care services and some closure of inpatient units.

Public Health England’s statistics on people with learning disabilities and the services and support available to them and their families[[35]](#footnote-35) reported that in 2013/14, overall 117,025 adults with learning disabilities were using some form of community service, most commonly day services (49,555 people), home care (43,025 people), professional support (21,035 people), and equipment and adaptations (11,095 people).

Dame Christine Lenehan’s review[[36]](#footnote-36) reported that the behavioural needs of this group, in addition to their learning disabilities, meant that mainstream child and adolescent services do not feel they have the right skills. There are Children and Young People's Mental Health Services that don’t accept children and young people with learning disabilities as they don’t feel able to offer them any interventions. Meanwhile many paediatric services do not see themselves as mental health professionals. This also means that in some areas neither group believe they are commissioned to deliver the service for this group of children and young people, meaning that these children fall through the gaps.

Paving the Way[[37]](#footnote-37), a resource on how to develop effective local services for children with learning disabilities and behaviours described as challenging, stated that between 100-200 children were still living in assessment and treatment units 3 years after the Winterbourne View concordat. It reported that over 1000 children with statements for learning difficulties or Autistic Spectrum Disorder were boarding in residential special schools, and over one third of them in another local authority area (plus many more in independent special schools).

The CQC inspections of specialist mental health services[[38]](#footnote-38) inspected and rated 44 community services: 42 NHS and 2 independent. Overall, 35 (80%) were rated as good, and 4 (9%) were rated as outstanding. Only 4 services (9%) were rated as requires improvement and 1 service (2%) was rated as inadequate. The quality of care across all of the 5 key questions was generally good.

Figure 1: Ratings for services for people with a learning disability or autism, as at 31 May 2017



CQC saw evidence of staff showing their commitment to supporting the physical health of people. Many services carried out comprehensive physical assessments and monitored patients with, or at risk of, cardio-metabolic disorders. Some inpatient services had on-site medical staff and others liaised with external specialist healthcare professionals about the provision of care.

Some community learning disability services had long waiting lists. However, staff in some services carried out rapid assessments and reviews of waiting lists to identify those patients most at risk.

The Learning Disabilities Mortality Review Programme key findings[[39]](#footnote-39) around issues with direct provision of care include:

* clinical failure in the treatment of people with learning disabilities while in hospital, and included missed assessments or tests, managing epilepsy and delays in giving fluids or nutrition
* overlooking physical illness and inappropriately assuming that a problem was due to the person having learning disabilities

failure by the care provider to meet the care needs as obligated in the contract.

The Learning Disabilities Mortality Review annual report 2017[[40]](#footnote-40) reported that, of the 958 people (aged 4 years and over ) whose death was notified to the programme after 1st April 2017, the median age at death was 58 years (range 4-97 years). For males it was 59; for females 56. The median age at death decreased with increasing severity of a person’s learning disabilities. People with profound or multiple disabilities had a median age at death of 41 years; those with mild or moderate learning disabilities had a median age at death of 63 years.

103 mortality reviews were completed and at the end of the review, reviewers were asked to provide an overall assessment of the care provided to the individual. In 79% of (n=81) reviews the care was assessed as either Grade 1 (excellent) or Grade 2 (good). A further 12% (n=12) were assessed as ‘satisfactory’ (Grade 3). The care received by 5 people (5%) was assessed as Grade 5 (falling short of best practice with the potential for learning from a fuller review of the death). The care received by 1 person was assessed as Grade 6 (having the potential for, or actual, adverse impact on the person).

Reviewers indicated that 13 (13%) people’s health had been adversely affected by 1 or more of the following: delays in care or treatment; gaps in service provision; organisational dysfunction; or neglect or abuse. Some examples of excellent care given were related to the provision of reasonable adjustments that health services have a duty to provide under the Equality Act 2010.

NHS Digital data on Health and Care of People with Learning Disabilities[[41]](#footnote-41) reports that almost 50% of patients with a learning disability received an annual learning disability health check in 2016-17. This is an increase from 43% in 2014-15.

### Specialist behavioural support

Dame Christine Lenehan’s review[[42]](#footnote-42) found that:

* there is an issue with a lack of out of hours provision for children and young people with challenging behaviour, across services. People regularly reported problems when crisis erupts during the evening or at the weekend and where the only available place of safety is the local accident and emergency department
* the current geographical spread of inpatient provision does not represent the population needs both in geography and in capacity. There is no suitable placement available for young people living in London and the South East, or throughout the South West. Distant services are put under pressure and placement decisions will inevitably affect family life
* there are particular challenges for children and young people with the most complex needs, such as severe autism, severe learning disability and mental health needs. There are few inpatient beds available
* a number of children end up in residential special schools as a last resort and there are real concerns about the level of professional health support available from psychiatrists, psychologists etc. in that setting
* there were concerns about Residential Special Schools due to placements of children made at crisis point, into services which were not adequately skilled or staffed to effectively meet the level of need. Additionally, concerns were raised around the challenge of admissions from schools into both inpatient children’s units and to adult inpatient settings, possibly accounting for the bulge in placements between 18 and 25. The cohort of children currently in 52 week placements (1,129 in 2016: NHS England figures) have a very similar profile of need to those currently in inpatient health settings
	+ 1. Resource impact

Recommendation 1.4.10 was identified as having a potential resource impact, due to providing additional capacity for people who need intensive support during a crisis. No national data exists for the current number of people being provided with intensive support during a crisis. The overall impact in England was not known.

* 1. Housing
		1. Summary of suggestions

Stakeholders suggested that having a range of housing options available for people with learning disabilities that cater for different needs and preferences, and people being able to choose where they live and who they live with, will improve quality of life. Living alone with support or in small scale housing was felt to be important to create a homely living environment that is less like a large institution. Variation in housing provision, and lack of available housing resulting in people having to move to a different area, or staying in inpatient services, were raised as issues. Stakeholders also felt that planning housing needs in advance rather than at short notice, and having security of tenure, are key areas.

* + 1. Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the committee’s discussion.

Table 6 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Housing | **Giving people a choice of housing** NICE NG93 Recommendations 1.5.1 to 1.5.8 |

### Housing and related support

### Giving people a choice of housing– Recommendations for local authorities, clinical commissioning groups and service providers

NICE NG93 – Recommendation 1.5.1

Commissioners should work with local housing and social care providers to identify the specific housing needs of adults with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability) and [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges). They should ensure areas have a range of housing and care options available that meet these needs and cater for different preferences and person-centred support needs (see also [section 1.2](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#enabling-person-centred-care-and-support)).

NICE NG93 – Recommendation 1.5.2

Enable adults to live close to their family, friends and community unless they choose not to or there is a compelling reason not to.

NICE NG93 – Recommendation 1.5.3

Where possible ensure that, wherever people live, they have security of tenure in line with the [Real Tenancy Test](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#real-tenancy-test).

NICE NG93 – Recommendation 1.5.4

When helping adults with a learning disability and behaviour that challenges choose where to live:

* provide information on the range of possible options
* take into account their preferences and any specific support needs or risks, including the impact of environmental factors on the person (see the recommendation on [environmental factors](https://www.nice.org.uk/guidance/ng11/chapter/1-Recommendations#early-identification-of-the-emergence-of-behaviour-that-challenges-2) in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions)
* give them advice on adapting their current home if needed.

NICE NG93 – Recommendation 1.5.5

Offer people the option to live alone with appropriate support if they prefer this and it is suitable for them.

NICE NG93 – Recommendation 1.5.6

If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. Involve people in choosing how many people, and who, they live with.

NICE NG93 – Recommendation 1.5.7

Offer adults housing outside their local community only:

* if it is what the person wants
* if it is indicated after a full assessment and planning process, which takes into account the person's preferences, needs and risks
* for a specified time that has been agreed with the person, or agreed in their best interests if they lack capacity to decide this – for example, if they are in crisis and there is no local placement available.

NICE NG93 – Recommendation 1.5.8

If someone is moving outside their local area, local authorities, clinical commissioning groups and commissioners should:

* establish the commissioner who is responsible for paying for the person's care and support
* ensure they will still have the support they need
* make a plan that enables them to return to their local area if they want to, or if it is in their best interests if they lack capacity to decide this.
	+ 1. Current UK practice

NHS Digital reports data[[43]](#footnote-43) on the Adult Social Care Outcomes Framework indicator on the proportion of all adults with a learning disability who receive long-term support services, who are recorded as living in their own home or with their family. 2017-18 data shows that 77.2% of all adults in England lived in their own home or with their family, with a range from 72.3% in the West Midlands to 88.2% in the North West.

The National Audit Office report[[44]](#footnote-44) on local support for people with a learning disability reported that the proportion of people with a learning disability living in the community with family or with their own tenancy has increased from 70% in 2011-12 to 75% in 2015-16.

Public Health England’s statistics on people with learning disabilities and the services and support available to them and their families[[45]](#footnote-45) reported that:

* in 2014/15, the most common living situation for adults with learning disabilities getting long-term social care support was settled living with family/friends (44,785 people)
* 3,215 people were living in registered care homes, 23,075 in supported accommodation, 12,425 in tenancies with local authorities, housing associations or registered social landlords and 1,195 people in sheltered/extra care housing.

A study exploring commissioning practices related to people with learning disabilities and autism in England[[46]](#footnote-46) sent questionnaires on commissioning services to all directors of adult services for local authorities in England (N=153) and chief operating officers (or equivalent role) of clinical commissioning groups (CCGs) (N=209). Local authorities returned a total of 45 questionnaires (response rate of 29.4%). Responses from CCGs covered a total of 55 clinical commissioning groups (a response rate of 26%).

The 3 main circumstances under which respondents said out-of-area placements were used were:

* as a ‘last resort’, when no adequate support or services are available locally and it is not possible to develop them in the required timescale. This is because of a shortage or lack of accessible housing or specialist services (e.g. autism, challenging behaviour, complex needs, forensic, assessment etc.)
* in a planned way, when individuals want to be closer to family who had moved away or they had moved out-of-area to attend school and no longer wish to return, or it is the expressed choice of individuals or family members

when local placements would not be appropriate due to forensic risks or previous victimisation.

NHS England’s commissioned report[[47]](#footnote-47) making recommendations to transform the commissioning of services heard from people with learning disabilities and/or autism that on being admitted to hospital, it was common to lose their tenancy.

The Equality and Human Rights Commission looked at the current provision of accessible and adaptable housing for disabled people provided by local authorities and registered landlords[[48]](#footnote-48). The report found that:

* implementation of the UK Government’s Transforming Care programme, which aims to take a person-centred approach, to ensure that people are able to exercise choice in accessing services (including housing), is very slow
* there is evidence that housing providers do not fully understand the requirements that people with learning disabilities or people with mental health conditions might have, and as a result they prioritise applicants with physical impairments over others
* disabled people, and in particular those with learning disabilities, sensory impairments or mental health conditions, report that they have difficulty getting adequate support from housing providers. This ranges from providers’ reluctance to supply information in accessible formats, such as ‘easy read’, to a lack of specificity in advertisements for accessible properties, and a lack of assistance with applications. This includes tenancy agreements and correspondence from the landlord, which typically contains language that is legalistic and inaccessible to many people, including those with learning disabilities.

stakeholders reported that ensuring that people were able to exercise choice and control over who they live with, who can visit and when, was very important and they gave examples of where this had been restricted. Concerns were raised by stakeholders that people with learning disabilities are not always able to exercise choice and control in this context.

* + 1. Resource impact

The recommendations in NG93 on housing (section 1.5) were identified as having a potential resource impact, due to providing additional capacity for additional suitable housing needs.

No indicative costs have been included in the resource impact products, as the guideline committee took into account that there is no single housing model to recommend and people have different preferences and support needs which may impact on the type of housing that is suitable for them. The overall impact in England was not known.

* 1. Short break services
		1. Summary of suggestions

Stakeholders felt that having short break services that are available when people need them, tailored to their needs and flexible can give people a break from stressful environments, improve resilience and prevent admissions.

* + 1. Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee’s discussion.

Table 7 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Short break services | **Short break services** NICE NG93 Recommendations 1.7.1 to 1.7.3 |

### Short break services – Recommendations for local authorities, commissioners and service providers

NICE NG93 – Recommendation 1.7.1

Local authorities must, in line with the [Breaks for Carers of Disabled Children Regulations 2011](http://www.legislation.gov.uk/uksi/2011/707/contents/made) and the [Children and Families Act 2014](http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted):

* provide a range of [short breaks](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#short-breaks) for children and young people with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability) and [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges) and
* publish as part of their Local Offer a statement of the range of services available and how eligibility will be assessed.

NICE NG93 – Recommendation 1.7.2

Commissioners in health and social care should provide sufficient, reliable, flexible and varied short break options, including both breaks away and support at home, for adults with a learning disability and behaviour that challenges.

NICE NG93 – Recommendation 1.7.3

### Ensure that short breaks are:

* community-based and close to home
* available based on need, and at short notice both in crisis and to prevent a crisis
* tailored to the needs of the person and their family or carers, taking into account the person's interests and preferences
* able to provide a positive experience for the person being supported
* able to deliver what is agreed in the education, health and care plan or care and support plan; carer's assessment; or behaviour support plan
* planned in advance wherever possible and involve people and their family members and carers visiting the service first to see if it is suitable and to get to know the staff providing it
* provided by staff who understand and respect people's cultural norms and values and their choices about personal care, private life and lifestyle.
	+ 1. Current UK practice

The National Audit Office report[[49]](#footnote-49) on local support for people with a learning disability found that many carers felt that there was not enough respite care.

* + 1. Resource impact

None of the recommendations were identified as having a significantresource impact(>£1m in England each year).

* 1. Inpatient services
		1. Summary of suggestions

Stakeholders highlighted an issue with long-term inpatient stays and people having no planned dates to leave, when planning for discharge should start as soon as someone is admitted to hospital. Stakeholders felt that different professionals involved in supporting people with learning disabilities in the community are unable to do so appropriately, and do not have the skills needed to manage the complexities of discharges and prevent admissions. Stakeholders felt that inpatient admissions should be a last option, and having placements close to home, having a named worker and regular review of the discharge plan (every 3 months) are important areas.

* + 1. Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the committee’s discussion.

Table 8 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Making the right use of inpatient services | **Exploring alternatives to inpatient admission** NICE NG93 Recommendation 1.8.1**When a placement is needed**NICE NG93 Recommendations 1.8.5 to 1.8.7**Planning and review to support discharge**NICE NG93 Recommendations 1.8.9 and 1.8.10 |

### Making the right use of inpatient services

### Exploring alternatives to inpatient admission – Recommendations for commissioners, service providers and practitioners

NICE NG93 – Recommendation 1.8.1

Admit children, young people and adults with a [learning disability](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability) and [behaviour that challenges](https://www.nice.org.uk/guidance/ng93/chapter/recommendations#behaviour-that-challenges) to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted.

### When a placement is needed – Recommendation for local authorities and clinical commissioning groups

NICE NG93 – Recommendation 1.8.5

Provide an inpatient placement that is as close as possible to where the person usually lives.

**When a placement is needed – Recommendations for inpatient services and community learning disability teams, including the named worker**

NICE NG93 – Recommendation 1.8.6

The named worker should support the person to maintain links with their family, friends and community (for example, members of their religious community) while they are in hospital, and give their family and friends information about their progress.

NICE NG93 – Recommendation 1.8.7

If people are admitted as inpatients outside their local area, social workers in the community learning disability team and the named worker should stay in contact with the person, and help them stay in contact with other key practitioners in their own area.

**Planning and review to support discharge – Recommendations for inpatient services and community learning disability teams**

NICE NG93 – Recommendation 1.8.9

As soon as the person is admitted, the hospital and community learning disability team should work together to develop a discharge plan.

NICE NG93 – Recommendation 1.8.10

Practitioners involved in the child, young person or adult's care and support should review the person's discharge plan at least every 3 months. Include in these reviews:

* the person and their family members or carers
* the practitioner responsible for agreeing discharge
* a specialist in behaviour that challenges.
	+ 1. Current UK practice

Assuring Transformation Data[[50]](#footnote-50) relating to patients with learning disabilities and/or autistic spectrum disorder receiving inpatient care commissioned by the NHS in England collected at the end of October 2018 shows that:

* 2,350 inpatients were in hospital at the end of the reporting period
* more inpatients were discharged (150) than admitted (125) to hospital in October 2018
* of the 150 inpatients who were discharged/transferred from hospital, 100 (68%) were discharged back into the community
* of the 125 admissions to hospital, 65 were first admissions, 25 were readmissions within a year of the previous discharge, and 35 were transfers from other hospitals
* of those in hospital at the end of October 2018, 1,355 (58%) had a total length of stay of over 2 years
* 1,210 (52%) of inpatients were in a non-secure ward, 1,140 (48%) were in a secure ward
* under half of the inpatients (43%) last had a review of their care over 6 months ago (1,020)
* 58% of inpatients have a date planned for them to leave hospital (1,365)
* approximately 40% of inpatients in hospital in August 2018 travelled over 50km.

The Mental Health Services dataset[[51]](#footnote-51) relating to NHS funded secondary mental health, learning disabilities and autism services in England reports that at the end of August 2018 (based on hospital spells data):

* there were 3,685 people with learning disabilities and/ or autistic spectrum disorders in hospital
* there were 1,325 admissions and 1,330 discharges, 87% of these were discharged back into the community
* Of these inpatients:
	+ 1,375 (37%) had been in hospital for over 2 years
	+ 165 (4%) had a delayed discharge
	+ 445 inpatients had a planned discharge date.
* Findings based on ward stays data:
	+ 3,690 ward stays reported for the end of the period
	+ 1,690 (46%) inpatients were in a Learning disabilities ward and 1,470 (40%) in an adult mental health ward
	+ 1,910 (52%) were in a non-secure setting, 1,670 (45%) in a secure setting
	+ 585 (16%) travelled over 50km from home to get to the hospital.

NHS England state on their webpage about Care and Treatment Reviews (CTRs)[[52]](#footnote-52) that:

* since 2015, thousands of CTRs have been carried out that are helping to reduce the number of people going into hospitals
* of the 1904 community CTRs recorded between April 2016 and May 2018, the outcome was a decision not to admit in more than 3 out of 4 reviews
* of over 350 children and young people who have had a community CETR since 2016, 79% resulted in a recommendation not to admit the child to hospital.

Respondents were asked if CTRs are making a difference to the number of discharges. 89% of people answered ‘yes’ to this question. Many people made the point that lack of appropriate provision in the community has a big negative impact on the numbers discharged, especially as representatives of these services do not often attend CTRs.

Dame Christine Lenehan’s review[[53]](#footnote-53) was told repeatedly that once children are in units there are no incentives to discharge them, and no focus on outcome planning and no-one in the system that pushes this or looks at next stage provision. The lack of available placements available for individuals to move to is an issue.

The Department of Health and Social Care’s consultation[[54]](#footnote-54) reported that responses reconfirmed concerns about the numbers of people with learning disabilities, autism and mental health conditions being admitted to hospital, often a long way from their home or family and friends, and against their wishes, and the negative impacts this can have. They heard about delays in transfers (e.g. as part of a step-down programme), and the impact this has on people and the costs to the system.

Respondents were clear that difficulties encountered by CCGs in accessing patient-level data have served as a major obstacle to reducing the admission of those with learning disabilities to inpatient settings. In particular, when dealing with people with complex care needs, a deficit of information on the part of CCGs means that they are unable to effectively plan for a reduction in the level of care provided when a person moves from an inpatient setting back into the community.

NHS England’s commissioned report[[55]](#footnote-55) to make recommendations to transform the commissioning of services for people with learning disabilities and/or autism heard that a barrier to discharge is often that responsible clinicians in inpatient settings will be concerned that appropriate support is not available in the community, and struggle to see how an appropriate community-based support package (potentially including continued assessment, treatment and safeguarding) could realistically be put into place. That can then lead to decisions that it is too early to discharge, or start planning for discharge.

The CQC inspections of inpatient services[[56]](#footnote-56), frequently encountered patients who had been in hospital for a long time. In some cases, care plans had a lack of discharge planning information.

* + 1. Resource impact

None of the recommendations were identified as having a significantresource impact(>£1m in England each year).

* 1. Additional areas

**Summary of suggestions**

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 18th December.

### Staff training

The training of staff to ensure they have the skills and competencies to support people with learning disabilities was suggested as an area of quality improvement. Specific skills that stakeholders felt that staff need training in include Positive Behaviour Support, how to do functional assessments and using least restrictive approaches to managing behaviour that challenges. Support from Practice Leaders was also raised.

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee is therefore asked to consider which components of care and support would be improved by increased training. However, training may be referred to in the audience descriptors.

### Functional assessment and positive behaviour support plans

Stakeholders suggested that all people with learning disabilities should have a functional assessment to identify reasons for behaviour that challenges, and have a positive behaviour support plan based on the assessment. These areas are within the remit of the NICE quality standard on [Learning disabilities: challenging behaviour](https://www.nice.org.uk/guidance/qs101).

### Medication

A stakeholder suggested the use of psychoactive medication as an area for quality improvement. Use of antipsychotic medication is covered by statement 6 in the NICE quality standard on [learning disabilities: challenging behaviour](https://www.nice.org.uk/guidance/qs101).

### Identification of learning disabilities and terminology used

A stakeholder suggested that identification of learning disabilities and consistent use of terminology across services are quality improvement areas. These areas are not covered by the NICE guideline on [learning disabilities and behaviour that challenges: service design and delivery](https://www.nice.org.uk/guidance/ng93).

### Transition from children’s to adult services

Stakeholders suggested that the transition from children’s to adult services is an area for quality improvement. This area is covered by the NICE quality standard on [transition from children’s to adults’ services](https://www.nice.org.uk/guidance/qs140).

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# Appendix 1: NICE quality standard on Learning disabilities: challenging behaviour (QS101)

**List of quality statements**

**Statement 1.** People with a learning disability have a comprehensive annual health assessment from their GP.

**Statement 2.** People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour.

**Statement 3.** People with a learning disability and behaviour that challenges have a designated person responsible for coordinating the behaviour support plan and ensuring that it is reviewed.

**Statement 4.** People with a learning disability and behaviour that challenges take part in personalised daily activities.

**Statement 5.** People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used.

**Statement 6.** People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions.

**Statement 7.** People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months.

**Statement 8.** Parents or carers of children aged under 12 years with a learning disability and behaviour that challenges are offered a parent‑training programme.

# Appendix 2: Review flowchart

Records identified through topic engagement
[n = 71]

Records identified through IS scoping search
[n = 20]

Records identified through ViP searching
[n = 1400]

Records excluded
[n = 1374]

Records screened
[n = 1491]

Full-text papers excluded
[n = 100]

Citation searching or snowballing

[n= 5]

Full-text papers assessed
[n = 122]

Current practice examples included in the briefing paper
[n = 22]

# Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

| ID | Stakeholder | Suggested key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| **General comments** |
|  1 | Department of Health and Social Care | Thank you for the opportunity to comment on the topic engagement for the above quality standard. I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation. |
|  2 | National Association of Independent Schools and Non-Maintained Special Schools (NASS) | Key area for quality improvement 1Clarity about whether or not, or the extent to which these standards apply to children and young people | Several of the key policy reference documents and specifically about children and young people but there is an explicit statement that the standard will not be about support to children or young people who display behaviours that challenge | There is non-statutory guidance on use of restraint for special school settings but nothing about behaviour that challenges alone and the legal position around areas such as deprivation of liberty are much less clear for children than for adults. |   |
|  3 | NHS Improvement Patient Safety | No comments. |
|  4 | Royal College of Nursing | This is just to let you know that there are no comments to submit on behalf of the Royal College of Nursing in relation to the stakeholder engagement exercise for the Service model for people with learning disabilities and challenging behavior quality standard. |
|  5 | Royal College of Psychiatrists | [RCPsych welcomes the opportunity to guide quality improvements linked to the Service model for people with learning disabilities and challenging behaviour. We have considered children and young people separately to adults with Learning Disabilities. Though they often have similar needs, they are not identical. We would suggest the following 13 improvements’. The first 7 refer to children with LD and the final 6 refer to adults with LD.](https://linkprotect.cudasvc.com/url?a=https%3a%2f%2fwww.nice.org.uk%2fguidance%2findevelopment%2fgid-qs10072%2fconsultation%2fhtml-content-3&c=E,1,3gFs37bF-l4uhbdqJgAfFg6Uou0rkf8nF34fJNa_39g860Y0Gh70B39jLOaS1V69L0yMXWEk4V1lUZaTl0CFjs-ShfqNFplgBoLPZGnMlqukZw,,&typo=1) |
|  6 | SCM 1 | Additional evidence sources for consideration | Transforming care evaluation report – progress is variable and nowhere has a comprehensive approach to support and services for this client groupNAO reports |

|  |
| --- |
| **4.1 Strategic planning and infrastructure**  |
| **Local leadership and joint commissioning** |
|  7 | British Association of Social Workers | Services for adults who have learning disabilities and display challenging behaviour should be jointly commissioned by health and social care. Service development should be in co-production with those who use services.  |  Joint commissioning of services simplifies the system experienced by individuals resulting in timely, appropriate support.  | There is evidence of variable experiences of service delivery – to jointly commission services reduces funding discussions and seeks to improve service delivery. This is especially important where an individual may be disaplaying challenging behaviour.  |   |
|  8 | Foundation for People with Learning Disabilities | Key area for quality improvement 3 | lead commissioner (acting on behalf of local authorities and clinical commissioning groups) is based on local need and understanding of the cost benefit of supporting someone who is described as challenging well from the beginning.Should commission service and support in the community. | Commissioners need to not be innovation averse. The planning, early planning, that prevents exclusion and placements away from home or local borough base, will yield better outcomes and less costly interventions. | [https://www.theguardian.com/society/2012/oct/26/winterbourne-view-care-staff-jailedhttps://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdftransforming the commissioning of services.](https://www.theguardian.com/society/2012/oct/26/winterbourne-view-care-staff-jailed) |
|  9 | Hertfordshire Partnership University NHS Foundation Trust (HPFT) | Key area for quality improvement 1Ensuring that services are planned that take a ‘whole life’ approach from early childhood onwards. | A ‘whole life’ approach to service planning and delivery would enable better planning and targeting of resources based upon identified need, a true focus on early intervention and the best basis for the use of pooled budgets and resources across health, social care and education. An additional key perceived benefit of this type of approach is the fostering of closer working relationships between care and support sectors, thus setting the scene for: smoother transitions between services; better continuity of care; the development of shared models and approaches; and shared cross-agency responsibilities. | Not having services currently commissioned and organised in this way is a significant barrier to effective service provision to children, young people and adults with a learning disability, including those who display, or are at risk of displaying behaviour that challenges. |   |
|  10 | Royal College of Paediatrics and Child Health | Key area for quality improvement 1Clarity about responsibility and accountability for provision of services in the full sense – planning, delivery, review, evaluation, oversight, including who to go to when there are difficulties Implement this in CQC inspections and the Health and Wellbeing Boards/equivalent Ensure RESOURCE IMPLICATIONS are addressed  | Responsibility frequently falls between service providers – e.g. ‘not mental health, so not Camhs’ role, and then nothing happens. There is a lack of expertise which results in no serviceThere are doctors dabbling in psycho active medication this creates risks out of desperation are taken in isolation from proper assessments and management as recommended in NICE guidance NICE guidance has real potential but can become meaningless without resources and precise accountability  | There are huge gaps nationallyChildren from many different Trusts are seen in specialist Learning Disability clinics, there are currently many reports of a lack of advice and help from parentsTrying to find a service wastes resources of professionals as the guidance quotes higher costs of family breakdown and out of area placements  | Surveys/Reports from Paediatricians and Camhs, parent organisations and charities  |
|  11 | Skills for Care | Clarity around support / PBS where local area teams and support services interact | Social care services can play an important part but in some places they are expected to deliver PBS without it being properly specified in their contracts | Services can be starved of the resources to do this properly, or reluctant to approach local support services in case they are seen as ‘failing’ and this can lead to no action until the placement breaks down | The failure of successive waves of the ‘winterbourne view’ / transforming care programmes to substantially reduce the numbers of people inappropriately living in hospital |
|  12 | SCM 1 | Key area for quality improvement 1 | Lead Commissioner in place with appropriate knowledge, skills and experience- accountable for strategic commissioning for educations health and social care services and support across children and adults | Currently lacking. Would enable a joined up holistic approach to support and services, and address the pitfalls of transition between child and adult services.Specialist knowledge would enable evidence based approaches and services to be commissioned to a strategic plan.Would address the conflict of interest re funding support and services across child and adults (i.e. children’s services invest to save funds for adults services | All evidence submitted / considered by the NICE guideline groupCB NSG charterEnsuring Quality Serviceshttps://www.theguardian.com/social-care-network/2016/feb/02/commissioning-will-be-key-in-changing-learning-disability-care Good practice guidance: https://ipc.brookes.ac.uk/publications/Commissioning\_for\_People\_with\_Learning\_Disability.pdf https://www.rcpsych.ac.uk/pdf/RCGP%20LD%20Commissioning%20Guide%202012%2010%2009%20FINAL.pdf  |
|  13 | SCM 2 | Designation of a single lead commissioner, who has in depth knowledge and experience of working with children, young people and adults with learning disabilities and behaviour that challenges to oversee strategic commissioning of health, social care and education services for all people with learning disabilities.  | A single lead commissioner, who has in depth knowledge and experience of working with children, young people and adults with learning disabilities and behaviour that challenges to oversee strategic commissioning of health, social care and education services for all people with learning disabilities is recommended by the NICE Guidelines.  | The need for a joined up approach has been emphasised by policy, by families of people with learning disabilities and by professionals. This is because such an approach facilitates better planning and decision-making at a service and individual level. NHS England, ADASS and LGA 2015, Building the Right Support found that. “Currently the approach to commissioning services for people with a learning disability and/or autism is fractured, with responsibility split between local authorities, CCGs and NHS England. It can be difficult to move funding from one agency to another, to enable the commissioning of less inpatient care and more preventative, community-based services and support.”A single lead commissioner is recommended by NICE Guidelines and builds on  | [NHS England 2014: Winterbourne View- time for change states, for example: “The basic pillars of what is required at a local level from NHS and local authority commissioners has already been described (and committed to by a range of partners) through the Transforming Care Concordat and elsewhere, namely:• One shared vision, driven forward by active senior leadership….” Council for Disabled Children (2017) These are our children: A review by Dame Christine Lenehan “There is little evidence of systematic cross-system commissioning with health and local authorities of good early intervention and therapeutic family support/short breaks services.” See also “pooling of budgets” below. It is obvious that the pooling of budgets is facilitated by having a shared strategic lead and vice versa.](https://www.england.nhs.uk/2014/11/learning-disabilities-action/) |
|  14 | SCM 2 | Pooling of budgets across health, social care and education | Pooling of Budgets across health, social care and education is recommended by the NICE Guidelines. | Fragmented budget holding impedes commissioning in line with recommended good practice, delays and imperils effective individual commissioning or purchasing decisions leading to poor outcomes for individuals.  | National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour found that the government did not achieve the main goal set in the Concordat to move all people, where appropriate, out of hospitals by 1st June 2014 because ‘no mechanisms existed for the systematic pooling of resources to build sufficient capacity in the community to enable it to happen’ (p38).NHS England 2014: Winterbourne View- time for change Recommends: “One pooled budget, allowing maximum flexibility for commissioners to fund what individuals truly need, and aligning the financial incentives on all commissioners to invest in community-based provision.” NHS England, ADASS and LGA 2015, Building the Right Support stated that:“CCGs will be encouraged to pool their budgets with local authorities whilst recognising their continued responsibility for NHS Continuing Healthcare. CCGs, NHS England specialised commissioning and local authorities will be supported to, where appropriate, put in place governance and financial mechanisms to align or pool resources and manage financial risk”.  |
|  15 | SCM 3 | A single point of responsibility for commissioning services for people whose behaviour challenges | Research evidence and PPI feedback suggests that services for people whose behaviour challenges are not well co-ordinated or not available at the right time | Early high quality support is crucial both to improve outcomes for children and adults with LD/autism and their families. Early support is also crucial to prevent high costs to services if problems are allowed to get worse. | See all evidence reviewed for the NICE guideline |
|  16 | SCM 8 | Realistic commissioning  | Mansell report Transforming CareBuilding the Right support Local support for people with a learning disability – NAO Personalised commissioning in adult social care – NAO Care services for people with a learning disability and challenging behaviour – NAO Transforming care – the challenges and solutions- VODG  | There is a raft of guidance regarding commissioning and this was preceded by guidance around personalisation. All of the guidance states that people should have the opportunity to leave where they belong and close to their own family if this is what they choose to do. Guidance is clear that in order to do this commissioners need to work with and develop the local provider market. This would also help with the housing situation. Transforming Care has not met its milestones and this in part is due to ongoing commissioning practice that is piece meal and not looking more strategically at the needs of this group. We need to consider this group for support in view of their lifetime not in short (more usual) commissioning periods of time. Commissioners are under pressure to reduce costs, this is often a realistic prospect for this group but only over longer periods of time. So the view needs to be around keeping the person out of hospital for all of their lives and not just in the next five years.  |   |
| **Planning and delivering services according to local need** |
|  17 | NHS England, Local Government Association and Association of Directors of Adult Social Services joint response | **Data and intelligence supporting strategic planning and early intervention** | There is clear evidence that sets out the importance of early intervention and preventive approaches in helping to reduce incidences of behaviours that may challenge services and/or the likelihood of restrictive interventions, including hospital admission. This includes behaviour that may result in people coming into contact with the criminal justice system.In order to do this, and to ensure the availability of the appropriate services and support, commissioners need to ensure a dynamic process for risk stratification of the local population of people. Within this dynamic risk stratification a key element is a local register of those most at risk of admission to inpatient settings with a focus on early intervention and support. | This is about good practice strategic planning and commissioning approaches to meet current and future need, working across children and adults services. Current service provision and early intervention services are variable across the country.In addition to directly commissioned support services it is critical that all areas have a good level of speech and language therapy expertise. In addition maintaining optional health of individuals is important to reduce pain or discomfort. Data on SALT and levels of annual health checks are a good measure of supportive preventative services.This approach can support increased vigilance for those individuals at high risk of placement breakdown / hospital admission ensuring proactive monitoring, as well as enhancing population-based strategic planning. | This approach was set out in the NHSE, ADASS and LGA service model for commissioners of services for people with a learning disability and/or autism who may display behaviour that challenges (as part of the Transforming Care programme):https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdfAnd in the supporting model service specification – this includes evidence base references, including in relation to the over-representation of people with a learning disability in the criminal justice system:https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdfData/evidence supporting early intervention in supporting children and families, includes:https://www.challengingbehaviour.org.uk/learning-disability-files/Briefing-Paper.pdfhttps://www.challengingbehaviour.org.uk/learning-disability-files/EIP-Evaluation-Report-Year-2.pdf |
|  18 | PBS4 | Key area for quality improvement 5Data driven approach to service delivery  | This is a key element of PBS described in the key components, but can be neglected in non-evidence based practices. Having data and making decisions based upon this data makes interventions and practitioners accountable and promotes transparency in decision making.  |   | Gore et al, 2013. Definition and scope of PBS.BACB code of conductNMC code of conduct |
|  19 | People First | Local disabled people must be more involved in their local decision making and service provision and decision making bodies, funding to meet support needs must be found only by disabled people being on their decision making structures will help you get service provision right there must be a link between local authority decision making and community groups to improve the lives of the local communitiesWhen support needs are identified they must be funded and supported well from cradle to grave  |
|  20 | People First | All local authorities in England and Wales to have a joined up support plan to meet the aspirations and support needs that all disabled people living in their area have these plans could be checked by the care quality commission or a government select committeeHow can services be made better for people with a learning disability and behaviour that challenges?Social care needs to be as well funded as the NHSYou have to understand that families with people with learning difficulties and behaviour that challenges are in crisis and therefore there are some political questions that only politicians can answer. How can you ask the family what support they need if you don’t go to them and ask what they need. They don’t have time to read the fancy leaflet they need a person from the local authority knocking on the door and asking what support do you need. Local authorities may know of people that are already using a service but I think that there will be many families that are struggling with no access to services I suggest that every local authority develop a scheme where they go and meet families and find out what they made a research project and develop the local Authority plan around what families are telling them on top of what their all ready is.• What would make the biggest difference?All of the above in a local authority plan local people will only know that the local authority is doing something for them if they can see the support that is being provided to them on a daily basis and the family are no longer in crisis because they can point to things that the local authority have supported them on |
|  21 | SCM 3 | Involve families in planning and delivering services | Research evidence and PPI feedback suggests that services for people whose behaviour challenges are not well co-ordinated or not available at the right time | Involving families makes services more responsive to the needs of patients and families. UK health and social care services are also committed to co-production and need to make this a reality | See all evidence reviewed for the NICE guideline |
|  22 | SCM 4 | Finding out what people need | 'It is really important that we find out what people need, more so we do this in a supportive encourage way. This is key to making the whole thing work. E.g. Whole-life / person centred planning that’s based on listing to what people need, helping people dream big and getting the right support/ an ordinary life. Needs to be done in an accessible way to meets everyone's needs e.g no access to spoken word.... ‘ |  |  |
|  23 | SCM 5 | All stakeholders work together to design service specifications for people who challenge services that include all environmental factors post-specialist assessment | This brings together many of the points in the enabling person-centred support, housing-related support and services in the community into one plan for the person in the guideline. | Evidence in my work of huge gaps in knowledge and skills in using assessment data to design capable environments for people who can challenge and discussed again at International BILD PBS conference in May 2018. | Sorry haven’t been able to find the evidence bases at short notice – some may be in AT data collection, CTR outcomes and pull much of this out of the NICE guidelines for LD and behaviour that challenges. |
| **Managing risk** |
|  24 | NHS England, Local Government Association and Association of Directors of Adult Social Services joint response | **Risk sharing arrangements, promoting a joint approach to support and the management of risk.** | Risk averse approaches can lead to overly restrictive interventions for people and a risk of over-supporting people. The experience of many people who have to rely on services for their support is that ‘risk’ is the reason given to them by services why they cannot do the things that other people are doing every day. There is lots of literature around good practice approaches in supporting people with a learning disability/autism; these set out the need to encourage and support independence and positive risk taking. To do this, professionals working with individuals and families need to be balance their professional duty of care to keep people safe whilst not being overly hindered by risk averse approaches.  | Achieving this is about professionals supporting each other in jointly agreed risk management approaches together with people and families, as part of good person-centred planning processes. This is consistent with approaches set out by the Royal College of Psychiatrists in relation to quality standards in inpatient settings, but equally apply to multi-disciplinary approaches for community-based arrangements – including as people are discharged from hospital and into the community.https://www.rcpsych.ac.uk/pdf/QNLD\_Standards\_3rd\_edition\_2016\_(2).pdfIn addition to risk sharing as a clinical or practical intervention it is important that finances are easily available to support short term additional resources. Having a “safety net” of funding may create a sense of an increased ability to manage should fluctuation in behaviour occur. | CQC Key lines of enquiry include proportionate approaches to risk management.https://www.cqc.org.uk/guidance-providers/adult-social-care/managing-risks |
|  25 | POhWER Advocacy | Key Area 4: Risk and risk management. |
| **Quality assurance** |
|  26 | Abertawe Bro Morgannwg University Health Board | Key area for quality improvement 3Support providers should be commissioned on a clear contractual basis to provide quality care based on current best practice i.e. PBS  | Commissioners should specifiy clear service standards based on available good practice  | Service contracts have a tendency not to adequately discribe service models or desired outcomesThis would greatly assist in and evaluation and improving quality, | <http://pbsacademy.org.uk/wp-content/uploads/2017/10/PBS-Standards-for-services-Oct-2017.pdf> |
|  27 | Abertawe Bro Morgannwg University Health Board | Key area for quality improvement 5Make explicit reference that service models and providers must reduce restrictive practices and address health in equalities | These are key current good practice requirements-widely recognised as important in the field | They address quality of life outcomes and reflect service quality and competence issuesSupport providers have key roles in addressing both issues | [http://restraintreductionnetwork.org/https://www.england.nhs.uk/learning-disabilities/improving-health/https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities](http://restraintreductionnetwork.org/) |
|  28 | The Challenging Behaviour Foundation | Safeguarding | People with learning disabilities are at risk of abuse. It is important that robust systems are in place to prevent and identify abuse of this group, with all areas working effectively, in coordination and communicating effectively to prevent abuse being missed.  | There is much evidence demonstrating how people with learning disabilities have a poor experience of safe guarding. Panorama revealed shocking abuse of people with learning disability at Winterbourne View Hospital in 2011. Since then safeguarding has continued to fail people with a learning disability.People with a learning disability are sectioned inappropriately, spending many years in units, experiencing abuse and neglect, including overuse of restrictive practices, not receiving any proper ‘assessment or treatment’ and not being able to get out and live a fulfilling life, with the right support in their local community. Evidence of this can be found in Mencap and the Challenging Behaviour Foundations ‘Out of Sight’ report, the report ‘Winterbourne View: the Scandal Continues’, and the Care Quality Commission and Challenging Behaviour Foundation’s ‘Three Lives’ report. There is wide recognition that people with a learning disability are being overmedicated in all settings. NHS England launched the Stopping the over medication of people with a learning disability, autism or both (STOMP) programme to help tackle this.There are many examples which highlight the poor experience of safeguarding for people with learning disabilities; the terrible abuse at Mendip House uncovered this year provides a recent example. |   |
|  29 | The Three Cs Support | 1.1.Achieving change: strategic planning and infrastructure. Least restrictive options should also embrace positive risk taking This needs to be agreed by all providers/stake holders. 1.1.14 Involving people in commissioning needs to be expanded. “make use of “ could be interpreted as tokenistic. This is not specific enough Any strategic plan needs to include a provision for people with autism. |

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| **4.2 Enabling person-centred care and support** |
| **Involving people and delivering support** |
|  30 | British Association of Social Workers | Key area for Quality Improvement 2Adults with learning disabilities who display challenging behaviour should receive support which is person centred and strengths based. | Individuals with learning disabilities should have access to appropriate care and support which is centred on their individual needs. It is essential that there is choice in respect of all aspects of support available and that this is not determined on geographical location.  | BASW and Shaping Our Lives have developed a joint charter for disabled adults which states• We will start with the disabled person’s own views of their situation, priorities, aspirations and preferences• We will be honest about what is possible and what is not• We will have conversations rather than being bound by forms and procedures • The conversations will be meaningful and will be about what disabled adults want. | [Please see joint charter between BASW and Shaping Our Lives - http://cdn.basw.co.uk/upload/basw\_52212-6.pdf](http://cdn.basw.co.uk/upload/basw_52212-6.pdf)  |
|  31 | The Challenging Behaviour Foundation | Understanding and use of effective communication | To ensure the involvement of people with severe learning disabilities and behaviour that challenge staff need to use appropriate and effective communication skills to be able to meet individual’s specific communication needs. | People who have a severe learning disability often do not communicate verbally, but may use other methods of communication, such as signing or using picture systems. Communication methods need to be unique and specific to each individual. This should include consideration to a person’s behaviour. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person’s needs or wishes are understood.  |   |
|  32 | Hertfordshire Partnership University NHS Foundation Trust (HPFT) | Key area for quality improvement 2People with a learning disability and behaviour that challenges should be supported to make choices and communicate their views regarding decisions that affect them.  | Actively involving people with a learning disability in all decisions that affect them is fundamental to achieving truly person-centred care and support.A lack of choice and control are often significant factors in understanding the context for the presentation of behaviours that challenge in the first instance.It is important that a person’s support network, both paid and unpaid, are involved if this is what the person wants. | This is an area in which we currently see a great deal of variation in practice. ‘Involvement’ can be tokenistic and not well informed.There is particularly a need for a greater emphasis on training and support for direct care staff in translating the principles of the Mental Capacity Act (2005) into day-to-day practice. |  |
|  33 | Milestones Trust | Presence of a person centred culture  | This allows a service which is responsive to individualised needs | Services are not routinely commissioned on this basis, and delivery is not monitored on this basis. The growing use of contract frameworks means that commissioning is price-led, and outcome monitoring remains haphazard. |   |
|  34 | Milestones Trust | Skills Development | A culture of giving people opportunities to develop, to learn from their own experiences, the opportunity to develop coping strategies and the chance to live fulfilled and meaningful lives is crucial | Placements are often seen as place-holders; there has been a shift away from developmental services and despite the rhetoric, outcome based commissioning and monitoring is rare. |   |
|  35 | NHS England, Local Government Association and Association of Directors of Adult Social Services joint response | **Care and support delivered on the basis of the principle of the capability of the environment in which that care and support is delivered.**  | Capable environments are characterised by: positive social interactions, support for meaningful activity, opportunities for choice, encouragement of greater independence, support to establish and maintain relationships and mindful and skilled family/carers and paid support and care staff. In many cases (as set out in Mansell etc.) we know that many of the environments in which individuals are supported are not always as ‘capable’ as they should be which can lead to behaviour that challenges. | See attached document for illustrative evidence. This is underpinned by a body of evidence in relation to good practice in supporting people who may display behaviour that challenges that suggests that characteristics of the social environment (such as social distance and aversive stimulation) may underpin the motivation of challenging behaviour (McGill, 1999). Therefore, altering such “motivating operations” then becomes a theoretically viable approach to preventing or reducing the occurrence of challenging behaviour in those at increased biological or developmental risk (*cf* Emerson & Einfeld, 2011).Stability of environment is critical. Many people experience eviction when behaviour changes and risk is perceived. There is a need to create homes that enable people to feel confident about their ability to remain. This can be done though good supportive tenancies or via Home ownership. | https://www.kcl.ac.uk/sspp/policy-institute/scwru/news/2014/newsfolder/McGill-et-al-Capable-environments.pdfThe importance of the principle of capable environments was also set out in the NHSE, ADASS and LGA service model for commissioners of services for people with a learning disability and/or autism who may display behaviour that challenges (as part of the Transforming Care programme):https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdfLGA an ADASS produced a guide for Home ownership that may be useful.https://www.local.gov.uk/sites/default/files/documents/HOLD%20and%20shared%20ownership%20and%20step%20by%20step%20guide\_FINAL.pdf |
|  36 | PBS4 | Key area for quality improvement 2Bespoke, personalised support is designed around the person to meet their needs individually, rather than fitting people in to existing services. | There is evidence that large scale support, and slotting people into existing services can lead to an increase in behaviours that challenge. There is evidence that personalised support achieves the best outcomes. |   | McGill/LGA/NHS England, 2015 Ensuring Quality ServicesMansell Report 2007PersonalisationBuilding the Right Support, NHS England, 2015Registering the Right Support, CQC, 2015 |
|  37 | People First | Getting out and about seeing friends and family doing things that people enjoy since 2010 has become harder because people have not got the support that they need independent living choice and control must be valued as equally as getting medical help from the NHS. Social care when needed, on demand. |
|  38 | People First | The care and support people and their families or carers should expectBecause everything is on line now people who are supporting disabled people do need support to find things online like the government safety net benefits support groupsLots of local authorities have closedown the very support structures that disabled people made these need to be rebuilt. The impact that the closure of services and advocacy organisations has had on people with learning difficulties needs to be taken into account when support decisions are made.Banking on line buying food and clothes onlinePaying bills onlineThese are every day tasks if mum and dad are 50 or above they can’t help you with this and it leaves you isolated and cut of from your local community. |
| 39 | People First | Please can you look at what the UN Convention on the rights of persons with disability says in your key areas and implement themAll services that people with learning difficulties young and old come into contact with must provide the information in Easy Read as their default position and everyone who works in the services that people with learning difficulties would come into contact with must know what Easy Read is where to get documents translated and that some people will always need independent support to understand information, which should always be available.Producing information in Easy Read must become as easy as getting up in the morning and going to work. At the moment it is not easy getting Easy Read information, it is like getting blood out of a stone, this is not how it should be in the 21st-century. |
| 40 | People First | Each individual will have their own method of communication this needs to be recognised in all policies going forward and whoever is working with them must prove that they are listening to the people that know the individual best but also listening to the individual so that it can be seen how, when, and in what way voices where heard in the decision making process to help them live as independently as they possibly can. |
| 41 | People First | Having support to find the services that would work for me would be a start and the information in easy read so I could understand what the services are offering four example all the information that the NHS provides is not in an accessible format to meet my access needs |
|  42 | POhWER Advocacy | Key Area 2: The availability of examples of options available in a story board format, with action and consequence illustrated of any strand of action. |
|  43 | Royal College of Psychiatrists | Key area for quality improvement 9Residential settings (care and/or education) should have appropriate commissioned access to multidisciplinary adult LD services- Psychiatry, psychology, OT, Speech and language therapy, LD nursing, behaviour support practitioners etc. |
|  44 | Royal College of Speech and Language Therapists | Ongoing and flexible communication support for people with learning disabilities. | There is good evidence that communication intervention for individuals with severe intellectual and development disabilities leads to positive changes (Snell et al., 2010). Communication support is often necessary for adults with learning disabilities and impacts on a wide range of activities of daily living, in turn effecting quality of life. Individuals will have varying and changing needs for communication support throughout stages of life therefore regular assessment and intervention is important.  | The UN Convention on the Rights of persons with disabilities states in article 21 that:“Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice...” (b) “...Including by accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions.” |   |
|  45 | Royal College of Speech and Language Therapists | All individuals who require assistive technology to aid or augment communication have access to specialist AAC services and equipment.  | NHS England has stipulated that 10% of AAC assessment and equipment provision should be carried out by specialist AAC centres. Local services are responsible for the ongoing support for this 10% of the AAC-using population, as well as for the assessment, provision of equipment and ongoing support of the remaining 90% (Gascoigne, 2012). | [The UN Convention on the Rights of persons with disabilities states in Article 9, 2(g) :“Parties shall also take appropriate measures to promote access for persons with disabilities to new information and communications technologies and systems, including the Internet.”](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-9-accessibility.html) |   |
|  46 | Royal College of Speech and Language Therapists | All individuals with learning disabilities and have swallowing difficulties should have regular re-assessment and appropriate intervention planning with the multi-disciplinary team. | Dysphagia (difficulties with swallowing) is common in adults with learning disabilities (Chadwick and Joliffe, 2008). If an individual has communication difficulties too then they may be unable to express discomfort with feeding and drinking and subsequently challenging behaviour.  |   |   |
|  47 | SCM 4 | Choice and control | ‘Choice of control is something we all take for granted, however people that access care and support often don’t have real choices ( let’s have real choices) who supports us, where we live, when we sleep and if we have sex! This is key to ensure people can make the right Decisions for themselves and their families, these decisions should not based on monetary or service provision but on what good and right for people. Choice is often tokenistic in service land e.g beds and opining in placements rather than what’s right for people.’ |
|  48 | SCM 4 | Planning care and support | ‘Personalise care and support planning is key to ensuring that the outcomes are met for people, these outcome relate to what people have said they need and want, in my experience this is fundamental to keeping on track and planning for an ordinary life , this is based on what people say and holding stuff together in times of challenge and growth... about people for people in accessible ways ( not by social works in jargonistic language)’ |
|  49 | SCM 6 | Engaging and working inclusively with people with learning disabilities and their family/carers. | There are numerous examples of the benefits of engaging with and working with people and their families as ‘partners’ in the care delivery process. Specifically, in relation to this area of care, having the experiential expertise of people and their family members can often help in problem solving, knowing the unique needs of the person and developing mutually agreed interventions.  | In the absence of working proactively and co productively with people and their families a number of inherent risks may arise; including:·         Limited input to the design and delivery of home-based treatment.·         Failing to recognise the unique contribution of people and families misses potential solutions and may alienate.·         Valuable learning and direct feedback in relation to support being delivered is missed/discounted. ·         The voice of people and families provide a vital source of critique for professionals/teams in terms of how they function and deliver support. | [http://static.carers.org/files/policy-and-resources-pack-final-low-res-4604.pdfhttps://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdfhttps://www.scie.org.uk/publications/ataglance/ataglance38.asp](http://static.carers.org/files/policy-and-resources-pack-final-low-res-4604.pdf) |
|  50 | Three Cs Support | 3.How do we empower and inform people and their families of their rights? How do we ensure that co-production is not tokenistic and actually influences and shapes decision making? |
|  51 | Three Cs Support | Supporting people to have meaningful employment even when they have challenging behaviours. |

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| **Coordinating care and support** |
|  52 | British Association of Social Workers | Key area for quality improvement 1People who have learning disabilities and display challenging behaviour should have a network of support around them who work in partnership.  | Individuals who have learning disabilities and display challenging behaviour should have a network of support around them including themselves, family, carers and professionals who work together. There is strong evidence that outcomes are improved when networks work together effectively.  | Evidence suggests that there is variance in individual’s experiences and that integrated working can bring forth challenges which need to be overcome in order to deliver best practice. Structures and processes must be in place to support inter agency working.  | [Please see BASW’s charter for Integrated Working at https://www.basw.co.uk/resources/basw-charter-integrated-working](https://www.basw.co.uk/resources/basw-charter-integrated-working)  |
|  53 | British Association of Social Workers | Key area for quality improvement 3Adults who have learning disabilities and display challenging behaviour need to have longstanding trusting relationships with their social worker. | Relationship based social work promotes good outcomes through supporting individuals to live independently reducing crisis situations arising.  | The named social worker pilot demonstrates the impact of relationship based social work practice. Social workers and other professionals must get to know the person they support and what is important to them – good social work practice takes time to develop relationships.  | [Evaluation of the Named Social Worker Pilot can be found at https://www.scie.org.uk/social-work/named-social-worker/summary-evaluation-findings](https://www.scie.org.uk/social-work/named-social-worker/summary-evaluation-findings)  |
|  54 | Mencap | Practical considerations | In all of this services need to ensure that they continue to work with the person and not do things for them (they need to be person centred) and there is a real benefit in having a named person responsible for coordinating the wider MDTs support to people.To develop teams’ skills commissioning that encourages models that include practice leadership (and roles to deliver this) and the funding needed to make this happen.Standards and guidance that makes it an organisational requirement to share learning with others, and collaborate, about the things that have worked well and that have led to an improved quality of life for people. |
|  55 | Milestones Trust | Engagement of all  | Each person with complex behaviours needs a network of support which includes families, friends, paid and unpaid support as well as professional and specialist input | Support and training for staff in building and maintaining relationships particularly with families is difficult to obtain. |   |
|  56 | OLM Group | Key individuals are identified to coordinate the persons Positive behaviour support plan, challenging behaviour support plan and reviews of functional assessments and transitions. | Consistent approaches and proactive support are maintained throughout the lifetime of the individual. This will increase the persons opportunities and reduce crisis situations from developing. The knock on effect is stability in placements, families remaining intact, The life long person centered plan is enhanced and consistent.Proactive coordination of care and personalised care and support planning will be improved. | The Mencap out of sight report 2013 states that services for learning disabilities and challenging behaviour are fragmented, ineffective and unresponsive. |   |
|  57 | People First | How staff can spot problems. And help put things right quickly.Knowing where accountability lies so that passing the buck is not an option First job is to build trust, there have been lots of abuse cases in recent years and lots of reports have written we must learn those lessons at the moment local authorities have said publicly that they have less money for social care this is true but a way needs to be found to help our politicians know that peoples support needs will never go away and are likely to become more complex at the same time people will want to hold onto their independence for as long as possible, people skills is crucial if the balance of seeing problems before they get to be a big problem is realised.  |
|  58 | Royal College of Paediatrics and Child Health | Key area for quality improvement 6There needs to be a focus on the design, delivery and coordination of support and services for children, not on the interventions and support |
|  59 | SCM 1 | Key area for quality improvement 2 | Every child young person and adult with a learning disability who displays behaviour described as challenging has a named worker who knows the individual and their needs and who co-ordinates their care and support | Co-ordination of support and services is essential to deliver good outcomes for individuals. The education health and social care systems are complex. Families often take on this role if they can but many people do not have families able to do This keyworker role has been identified repeatedly over many years as an intervention that would make a significant difference. | All evidence submitted / considered by the NICE guideline group |
|  60 | SCM 2 | Named co-ordinator | NICE recommends that children, young people and adults with learning disabilities whose behaviour challenges should have a named worker whose roles include co-ordinating care with and for the person and keeping them and their family informed.  | A lack of co-ordination of professionals’ and services’ efforts and a lack of effective interagency and inter-personal communication continue to lead to a failure of effective support to people and their families including in care and support delivery, planning and management of change. | [The government public consultation on No Voice Unheard, No Right Ignored (2015) made a commitment to pilot a named social worker initiative, explaining it as follows: “we see the role as championing the rights and views of vulnerable people, listening to people, understanding their wishes and desires, supporting them to live independently and in the least restrictive setting, and challenging other professionals in the system whilst being a partner in the system .”Health Education England, Skills for Care and Skills for Health (2017) have expanded upon this specifically in the context of Transforming Care and outlined equivalent roles in health. Dame Christine Leneham’s review recommends that: “each child or young person in an inpatient setting (due to their mental health, autism and/or a learning disability) or at risk of going into an inpatient setting (due to their mental health, autism and/or a learning disability) who does not already have an individual performing this role should have a keyworker/ named worker either from health or local authority services, but in touch with both”. Council for Disabled Children (2017) These are our children: A review by Dame Christine Lenehan](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/409816/Document.pdf)  |
|  61 | SCM 7 | Finding out what people need | ‘Having that person in charge can bring a level of accountability. It is helpful having that point of contact. I also like that it is about co-production and that the money follows the ‘service user’. Having a Commissioner that understand behaviours that challenge will help.’ |

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| **Care and support planning** |
|  62 | British Institute of Learning Disabilities | Co-production, including family input, into support planning. | People with LD and challenging behaviour need to consent to their planned support, unless they lack capacity to so do and yet often they are not involved in planning their support or what they are supported in. Challenging behaviour is more likely if people aren’t engaged in activities that have meaning or value for them and if they feel that staff control that which they do. Family members are also often not involved or consulted around planned support, despite services claiming to be person- centred and engaging with the person’s ‘circle of support’. Finally, staff who support the person day by day are often not involved in agreeing planned support, despite often spending the most time with the person and having vital insight into the best ways to support the person. | If someone feels they have control over how they live their life they are more likely to have a good quality of life (as quality of life is subjective and an individual is the person who knows whether that which they spend their time doing is of meaning, fulfilling, satisfying or joy making. Having a good quality of life makes challenging behaviour less likely and actively supporting someone to improve the quality of their life is fundamental to PBS. Family members often have a unique insight into what is important to the person, rather than simply what is important for the person.Support workers are more likely to be committed to and to follow a support plan that they have been involved in producing rather than a plan produced at some distance from the person. |   |
|  63 | Mencap | Developing a better understanding of why people use behaviours that challenge | There needs to be a greater focus and understanding of trauma for both people supported by services and the general population of support staff.A clearer and more explicit focus on functional assessments to form the basis of intervention plans. Some degree of clarity around who should lead with this (LA or providers). If providers, there needs to be some consideration towards the extra financial burden this resource will have on both large and smaller providers. A clear description that outlines the responsibility for Local Learning Disability teams to provide support for functional assessment and development of PBS plans (and actually be measured by their ability to do this in realistic timescales). | Many people supported have experienced some level of trauma in their lives.  |   |
|  64 | OLM Group | At least six monthly reviews of assessment and plan of care to be carried out with the person not for them. | Regular reviews of the assessments and plan of care improves the wellbeing of the person.Fewer hospital and institutional care stays.Care and support will be person centered, planned and proactive this will avoid the need for reactive actions when crisis occur.The person and their support network are kept in control of their care and support needs. Access to specialist health and social care services are identified and acted on. | The NHS digital 2018 Learning Disability Services Statistics evidence that just under half of people had a review of their care over 6 months ago. This means that there are at least half who have not had a review of care in the last six months.NHS England 2017 Developing Support and Services for Children and Young People with Learning Disabilities, Autism or both identified that proactive support is not readily available. Support is offered as a reaction and is fragmented resulting in the person losing control of their care. | NHS Digital 2018 Disability Services Statistics |
| 65 | People First | How staff and services work better together to give the right support.A lot of damage has been done since 2010 to present day there must always be a path for people with high support needs to have their say and voices heard whatever level of ability they have must go into their support plan so that voice is heard and they are at the heart of decision making rather than being on the sidelines. Choice control and independence must be at the heart of putting support plans together.  |
|  66 | POhWER Advocacy | Key area 1: Assurance about continuity of a service that is available /or is proposed. |
|  67 | POhWER Advocacy | Key Area 3: Assistance about dealing with change. |
|  68 | SCM 7 | Planning care and support | ‘Planning isn’t consistent enough.It is a fundamental pillar of care. I like that it has a named worker to make things consistent and that it focuses on choice for a person and planning early intervention if necessary. Also co-production involving everyone in writing the plan.’ |
|  69 | Three Cs Support | [1.6 Services for children and young people. Service reviews should include the person and their family as well as professionals.](https://www.nice.org.uk/guidance/ng93/chapter/Recommendations#services-for-children-and-young-people)  |
| **4.3 Early intervention and support for families and carers**  |
|  70 | The Challenging Behaviour Foundation | Supporting, engaging and working with families | Supporting, working and engaging with families and carers is an important consideration in ensuring effective care of people. This is especially important in the care of someone with severe learning disabilities and behaviours that challenge.  | Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. The National Service Model recognises the importance of involving family carers and other people who know the individual well in their care. Research has shown directly helping families of children and adults with learning disabilities is crucial to ensure the provision of capable and supportive environments for individuals whose behaviours challenge and to ensure a good quality of life for all. Families are diverse – their individual circumstances vary, so understanding each family context is essential to offering appropriate support. However, the involvement of families is not always taking place. Findings from the NHSE Building The Right Support evaluation showed that it can be a struggle to involve families.  |   |
|  71 | Foundation for People with Learning Disabilities | Key area for quality improvement 1 | Early intervention and support for individual and their family. Early intervention at the point of referral crucial in ensuring that things do not reach crisis. This will require the best practitioners, who may be in mainstream, are responding quickly and allocate one of the team to be the link for the family. This should be EARLY in order to avoid exclusions from school or services and allow the person to remain in their familiar environment | [http://pavingtheway.works/this provides a guidance of how positive change and support can be managed and supported.Paving the way to an ordinary life for children with extraordinary needs.https://www.challengingbehaviour.org.uk/learning-disability-assets/positivebehavioursupportworkshops.pdfpeoples needs can be met with good planning based on a true image of who the person is and what keeps them healthy and well.](http://pavingtheway.works/this%20provides%20a%20guidance%20of%20how%20positive%20change%20and%20support%20can%20be%20managed%20and%20supported.Paving%20the%20way%20to%20an%20ordinary%20life%20for%20children%20with%20extraordinary%20needs.) | [https://www.gov.uk/government/publications/early-intervention-the-next-steps--2 how to eliminate costly interventions](https://www.gov.uk/government/publications/early-intervention-the-next-steps--2%20how%20to%20eliminate%20costly%20interventions) |
|  72 | Hertfordshire Partnership University NHS Foundation Trust (HPFT) | Key area for quality improvement 3Families and carers of children, young people and adults with a learning disability and behaviour that challenges should be able to access a range of specialist social care and health services in the community. | It is important that support is provided to carers of people with behaviours that challenge to help them to:·         Manage their role as carers; ·         Care for the person and meet their need, in relation to behaviour, care and support, physical health, mental health, educational needs or ay offending behaviour;·         Access support from specialist services when needed.In turn, the anticipated benefits could include: increased carer knowledge, skills and confidence; less dependence on health and social care services over time; and a reduced risk of breakdown of family placements and inappropriate placements or admissions to inpatient services. | There is a particular need to improve the focus on the importance of early intervention with the right support for family carers, and to ensure services are responsive to fluctuating need over the life span. | - |
|  73 | Mencap | A focus on early intervention and family experience | There needs to be more work with families and early intervention. This links back to point 1. If there is a greater focus on supporting families and early intervention this will help reduce the potential for childhood trauma. |   | The importance of early intervention is well-recognised. See literature related to the Transforming Care programme/ NHSE Building the right support. |
|  74 | POhWER Advocacy | Key area 5: How to complain if I am not satisfied with Care/Support to ensure my wellbeing. |
|  75 | Skills for Care | Earlier intervention, easily available; both in support for families with young children (or as soon as behaviours of concern become apparent) and also for adults as early as needed  | Too much support is reactive – only offered once behaviours have become entrenched / dangerous | If behaviours of concern were understood as communication at a young age and families enabled to respond appropriately then those behaviours would not become more extreme and entrenched |   |
|  76 | SCM 1 | Additional developmental areas of emergent practice | Early intervention training and support for families (e.g. E-pats, CBF training) |   |   |
|  77 | SCM 1 | Key area for quality improvement 4 | Families are proactively supported with accessible, timely and practical information about supporting their relatives and services and support available to them | Families provide significant, long term and ongoing support to their relatives – but they need to be supported themselves in this role.Currently support available for families, and the quality of it, varies considerably | All evidence submitted / considered by the NICE guideline group |
|  78 | SCM 7 | Families and Carers | ‘It speaks for itself. The well-being of the family is important. I’ve seen it for my own experience and in others. This needs to be consistent. I like the training and info it had in it. |
|  79 | SCM 8 | Early Intervention and Response  | NICE Guidance NG93.identifies that early intervention is vital to support young people to be able to stay at home and to maintain the family unit for as long as possible. The document Autism in under19’s also stresses the importance of people staying within the family setting. Nice Guidance NG53- identifies the need for support for families throughout admission  | Families are often the only consistent part of the support around a person, as support staff and professionals change, families remain. Families continue to cite the need to fight for support that they are entitled to. Many families are managing as best they can without any formal training or support. Planned early intervention strategies could reduce the need in the young person to use behaviour that challenges as a mean for communication.  |   |
|  80 | SCM 8 | Key area for quality improvement 2 | Families and support NICE Guidance NG93Nice Guidance NG53 | Families with older children in an emergency have no support to call on at short notice; they are advised and left with no other choice than to call the police. Mostly what families need at this time is the physical presence of someone else. This type of emergency service could be commissioned and delivered by experienced social care providers. Families are often faced with trying to support their family member through an incredibly complex system. Trying hard to do what’s best for their family member whilst maintain their own lives and the rest of their family unit. Families are often only signposted to independent advisors once they have tried and been let down by statutory professionals. If families had a key contact that could support them in all areas then they would have access to timely and accurate information. This again doesn’t not have to be someone who is medically trained as is often thought. If this role sits outside of statutory services there may be a chance of more longevity.  |   |
|  81 | SCM 9 | Training for families to manage children and young people with behaviour that challenges | Early intervention and parental training would reduce the need for services both at the time and in the future. Quality of family life would improve. | Training for family members has always been very patchy at best and non-existent at worst. Increased understanding would help with parental/professional rapport. A consistent programme of training for families would reduce costs to services. | Families regularly reporting that they would like training. Despite knowing their child well, comments often suggest a lack of understanding of their child's condition and unrealistic expectations of their child's abilities (sometimes believing them to be more capable than they are and sometimes less)Learning disabilities and behaviour that challenges: service design and delivery (2018) NICE guideline NG93. Recommendation 1.4.2 |
|  82 | Three Cs Support | [1.3.Early intervention and support for families and carers. Support should be available to manage a “whole life” approach for carers as well as people being supported?. Information on rights is vital for carers, not just information on services available.](https://www.nice.org.uk/guidance/ng93/chapter/Recommendations#early-intervention-and-support-for-families-and-carers)  |
| **4.4 Services in the community**  |
| **Developing services in the community** |
|  83 | British Institute of Learning Disabilities | Physical and mental healthcare of people with LD and challenging behaviour. | Physical ill-health, pain, discomfort, sensory processing differences and poor mental health are all vulnerability factors for challenging behaviour (Hastings et al 2013).Staff supporting people with learning disabilities and challenging behaviour to access primary and emergency healthcare are additionally challenged by the lack of willingness to make reasonable adjustments to processes and systems, lack of understanding of some healthcare professionals and lack of specialist staff (eg LD liaison nurses in acute settings). This means that people with LD and challenging behaviour do not always get the same access to services and treatment as other people. | Improving access to the full range of health screening, reasonable adjustments to methods of accessing primary and emergency healthcare and better understanding in health care professionals of the needs of this patient group potentially could have a significant impact on patients’ health and so levels of challenging behaviour. Direct contact staff would feel more confident in their ability to support patients with challenging behaviour to access healthcare.Supporting good physical and mental health as people with LD age is especially important and yet an understanding of the changing needs of aging people with LD are not always considered by services, despite. PBS emphasising support to achieve a good quality of life across the lifespan. |   |
|  84 | Foundation for People with Learning Disabilities | Key area for quality improvement 2 | Keeping people described as having challenging behaviour supported in their community. | [http://pavingtheway.works/avoiding expensive systems that do not work and are costly.This is when we go back to early interventions](http://pavingtheway.works/avoiding%20expensive%20systems%20that%20do%20not%20work%20and%20are%20costly.This%20is%20when%20we%20go%20back%20to%20early%20interventions) | http://eprints.lse.ac.uk/336/1/dp1930.pdfthe cost of placements out of borough are expensive and do not support the needs of people described as challenging. An intensive support at point of referral with a link practitioner that keeps an eye will save money in the long run as people will have a life designed in line with their needs, dreams and communication. |
|  85 | NHS England, Local Government Association and Association of Directors of Adult Social Services joint response | **Equitable health and wellbeing outcomes from mainstream health services.**  | Mainstream health and social care services can and should meet a large proportion of people’s everyday needs.Shared commitment to the principle of mainstream services that are able to support people with a learning disability and/or autism, making reasonable adjustments where necessary, with access to specialist multi-disciplinary community based health and social care expertise as appropriate. A key function of specialist community teams for people with a learning disability/autism should be to support and work with mainstream services to develop their ability to deliver individualised reasonable adjustments, to support people directly.  | There is a vast evidence base for the health inequalities of people with a learning disability.From a broader wellbeing perspective, sport and Leisure services could ensure that people can access and enjoy community facilities by making reasonable adjustments. Good examples include specific film nights for autistic people or supermarket quiet times for shopping. | [Death by indifference Mencap (2007)Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study Learning Disability Mortality Review LeDeR Programme University of Bristol74 deaths and counting Mencap (2012)](https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf) |
|  86 | Royal College of Paediatrics and Child Health | **Key area for quality improvement 4Agreement that tertiary specialist services can be accessed and funded when local services feel inexperienced in certain circumstances/conditions**  | This may be needed for multiple obvious reasons They are usually very helpful if a true specialist centre – as with any medical condition but there are funding barriers NHS central commissioning would help for some conditions  |   | e.g. the Learning Disability behaviour and mental health specialist team at the Maudsley are very helpful and effective  |
|  87 | Royal College of Paediatrics and Child Health | **Key area for quality improvement 2Multi-disciplinary assessment and delivery teams that are planned and resourcedThis could be generic or specialist but Learning Disabilities should not take second place** | This is lacking and needed the current guidance is aspirational but is avoidant of current service pressures There needs to be input at earlier stages rather than waiting until costly crises breakdownIt is not easy for non-specialists and they can easily say no. The Learning Disabilities population must not take second place or be considered too difficult to provide for | It currently falls between services and professionals who work to their different organisations ‘criteria and external measures’ standardsCommissioners vary considerably in their knowledge and oversights can often happenFinancial pressures are also very severeThere are currently professional gaps in Camhs and Paediatrics but good planned specialist teams are very effective and long-lasting  | The Brighton and Hove Paediatric Learning Disability Camhs team experience was very positive. They had an excellent resolution of the previous rates of out of area and residential placements for challenging behaviours  |
|  88 | Royal College of Psychiatrists | Key area for quality improvement 6Development of local challenging behaviour alternatives to inpatient admission for CYP with LD eg Ealing model, Bradford best model. To avoid the use of inpatient units for challenging behaviour, alternative evidence based approaches are required. |
|  89 | Royal College of Psychiatrists | Key area for quality improvement 12Development of local challenging behaviour alternatives to inpatient admission for adults with LD. |
|  90 | Royal College of Psychiatrists | Key area for quality improvement 4There should be access to appropriately commissioned specialist multidisciplinary LD-CAMHS in all geographical areas (to eliminate the current post-code lottery)- see RCPsych CR200 for suggested numbers of staff. |
|  91 | Royal College of Psychiatrists | Key area for quality improvement 2Residential settings (care and/or education) should have appropriate commissioned access to multidisciplinary LD-CAMHS - Psychiatry, psychology, OT, Speech and language therapy, LD nursing, behaviour support practitioners etc. Often this is lacking in the offer when placed in private residential setings. |
|  92 | Royal College of Psychiatrists | Key area for quality improvement 7LD CAMHS and CAMHS services should have clear pathways/links with local community and specialist paediatric colleagues to support physical health needs being met. Challenging behaviour may be due to physical health reasons, mental health reasons, environmental or communication issues. Missing physical health, may result in a CYP being managed for their behaviour, without resolving the cause. The links will also serve to meet the mental health and behavioural needs of CYP who are being seen within physical health services. |
|  93 | Royal College of Psychiatrists | Key area for quality improvement 13Adult LD services should have clear pathways/links with local community and specialist physical health colleagues to support physical health needs being met. Eg GPs, neurology, gastroenterology, cardiology, endocrinology etc. |
|  94 | SCM 2 | Community based support  | It is fundamental to improving outcomes and to the NICE guidelines that “children, young people and adults with a learning disability and behaviour that challenges should have the support they need to live where and how they want”. The Guidelines purpose is to “help local areas shift their focus towards prevention and early intervention, enabling children, young people and adults to live in their communities, and increasing support for families and carers. This should reduce the need for people to move away from their home or community for care, education or treatment”. | [NHS Digital (2018) Learning Disability Services Statistics demonstrate continued placement into and use of in-patient facilities by often far from home of people with learning disabilities who have behaviour that is challenging. Provision which is distant from home but is not in in-patient services, is also widely used. Children and young people frequently are placed far from home to receive care support and education. Adoption of the NICE guidance would be highly likely to be associated with a shift in the proportion of Local Authority and NHS resources expended in favour of those spent within or near the local area and on community provision and against those spent further afield and on in-patient provision. It is suggested that this could be developed into a quality standard and indicators.](https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics)  | The need for this is at the heart of (amongst other policy documents, reports and audits):NHS England 2014: Winterbourne View- time for change NHS England, ADASS and LGA 2015, Building the Right SupportNHS England, ADASS and LGA (2015) Building the Right Support: Service Model National Audit Office (2015) Care services for people with learning disabilities and challenging behaviourCouncil for Disabled Children (2017) These are our children: A review by Dame Christine Lenehan |
|  95 | SCM 6 | Providing integrated and responsive community support to people within their own communities.  | There are important benefits of providing integrated support to people with learning disabilities and behaviour that challenges. When services work together in an integrated way outcome tends to be much more effective.  | The social construct of challenging behaviour and the applied interventions often used, are known to be much more effective when delivered as part of an integrated approach which sets out explicit accountabilities for various stakeholders and helps to build holistic/meaningful behavioural support for the person/their family.  | [https://www.nhsconfed.org/-/media/Confederation/Files/Publications/Documents/encouraging-integrated-working.PDFhttps://www.kingsfund.org.uk/sites/default/files/Evidence-base-integrated-care2.pdf](https://www.nhsconfed.org/-/media/Confederation/Files/Publications/Documents/encouraging-integrated-working.PDF) |
|  96 | SCM 9 | Commissioning of services for children and young people with learning disability, autism and behaviour that challenges | Significant numbers of children and young people still being placed out of area, raising costs, reducing ability of professionals to monitor progress and isolating children and young people from their families. This practice also makes it difficult for adult services, who then need to bring the young people back into new services when they go through transition | Likely considerable variation in the commissioning of local services for children and young people. Believe this could be improved nationally to reduce numbers of children and young people being placed out of area. Services also relying on unrealistic amounts of buildings based respite, which cannot easily be replicated in adult services. | Persistent patterns of commissioning over a long period, despite representations to make changes.Learning disabilities and behaviour that challenges: service design and delivery (2018) NICE guideline NG93. Recommendation 1.6.2 |
|  97 | Three Cs Support | [1.4 Services in the community – prevention, early intervention and response. A “whole life” approach should include utilising the full range of social inclusion activities , including employment, leisure etc as a way in to preventing crisis. More detail is needed on how local authorities will make the connections between the criminal justice system and local authorities.](https://www.nice.org.uk/guidance/ng93/chapter/Recommendations#services-in-the-community-prevention-early-intervention-and-response) |
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| **Specialist behavioural support** |
|  98 | Mencap | More flexible support at times of crisis | To help prevent admission and readmission to hospital and secure settings there needs to be a greater access to highly specialised services at times of crisis. People may benefit from access to support at times of intense crisis from trained and skilled intensive support teams working with people in their homes or using short stay respite services (not hospitals). | Evidence from the Transforming Care programme shows that there are still too many people with a learning disability being admitted and readmitted to inpatient settings and there is still a lack of robust community support across the country including intensive support services and flexible social care options. | The importance of intensive support teams and flexible social care options at times of crisis to help avoid inpatient admission, and to help prevent crisis in the first place is well-recognised. See literature related to the Transforming Care programme/ NHSE Building the right support. |
|  99 | People First | When a person with learning difficulties needs support that support should be provided in the local authority where the family lives or the place a person knows (because they have lived there all of their lives), this should become the norm.  |
|  100 | PBS4 | Key area for quality improvement 4Post incident support, such as debriefs are in place. This ensures employees well being is promoted and a learning culture from incidents is in place.  | This is recognised good practice in promoting the well being of employees and learning from incidents |   | NICE QS154 |
|  101 | SCM 1 | Key area for quality improvement 3 | Specialist behavioural support is available in the community and proactively targeted for early intervention and prevention to individuals at risk of developing challenging behaviour |   | All evidence submitted / considered by the NICE guideline group |
|  102 | SCM 3 | Provision of specialist challenging behaviour teams in each local area of the country | The only higher quality evidence for models of delivering challenging behaviour services suggests that referring people to a specialist challenging behaviour team delivers improved outcomes and is cost-effective (especially Hassiotis et al 2009 RCT) | Lack of expertise in supporting professionals is likely to make problems worse, and availability of expert support is reported by families currently as patchy across the country. | See all evidence reviewed for the NICE guideline |
|  103 | SCM 5 | Forensic teams are established, trained in specialist forensic interventions for LD, and are preventing admissions to out of area, hospitals or prison settings | To ensure that these are resources are properly put in place so they can be effective p.26 guideline | Aware of teams being seconded temporarily on 2 days a week | Sorry haven’t been able to find the evidence bases at short notice – some may be in AT data collection, CTR outcomes and pull much of this out of the NICE guidelines for LD and behaviour that challenges. |
|  104 | SCM 5 | Provide opportunities for professionals and supporters to reflect on support delivered and meet to review lessons learnt post-crisis  | In order to ensure care and support continues to be accessible, responsive, personalised, and evidence-based re page 24 guideline | This is not standard practice with all care providers to pressure of costs and is often in not n tenders or contracts. | Sorry haven’t been able to find the evidence bases at short notice – some may be in AT data collection, CTR outcomes and pull much of this out of the NICE guidelines for LD and behaviour that challenges. |
|  105 | SCM 6 | Additional developmental areas of emergent practice | Considerations of the importance of linking this work with the developing policy focus on localities creating forensic community teams for people with learning disabilities  |
|  106 | SCM 9 | Organisation of Specialist Support Teams | SSTs will play a significant role in keeping people in the community and in supporting successful discharges from secure settings | Locally (in North West) SST being set up is covering a very large geographic area. Unsure at this point whether crisis support can be effectively delivered across such a large area when team members may be a considerable distance from some of those they are seeking to respond to. Comparative study across the country may demonstrate ways to improve quality | Again, doubts being expressed by professionals about the ability of SST to respond effectively in a crisis. My own experience (in 1990s) of responding in a crisis in a much smaller area was that crisis was usually over by the time I arrived. Skilled out of hours response is essential to help prevent admissions.Learning disabilities and behaviour that challenges: service design and delivery (2018) NICE guideline NG93. Recommendation 1.4.10 |
| **4.5 Housing**  |
|  107 | Abertawe Bro Morgannwg University Health Board | Key area for quality improvement 2The sections on community services are generally good but more direct emphasis should be made to PBS being the recommended framework in both sections. As described above.In terms of and housing and related support greater emphasis should be plaed on the need for small scale community based ordinary housing with appropriate levels of support from staff who are knowledgeable and skilled in PBS | There is good evidence that small scale ordinary housing is the best physical (bricks & morter) housing service model, providing people with severe ID and challenging behaviour are supported by staff who are competent in PBSThe supported living model should be referred to directly and the cost savings and other advantages of this in relation to large scale residential care discussed. The benefits of third sector value based organisations should also be highlighted.It should be clarified that mental capacity is not a criteria for holding a tenancy agreement.  | There is a lack of suitable accommodation and high quality PBS based supportThere are still 3625 people from England with LD& autism inappropriately placed in hospital settings Similar proportions are likely to be the case in Wales and ScotlandWe continue to see the development of large scale private hospitals and residential homes, by private sector profit making organisations. Targeted at this client group. The inappropriate ‘trade in people’ continuing for this client groupThere is confusion regarding tenancy issues and many people are being denied the right to hold a tenancy based in ignorance and misunderstanding that if a person lacks mental capacity they cannot hold a tenancy agreement | Learning Disability Service Statisticshttps://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/provisional-statistics-at-july-2018-mhsds-may-2018-finalsee for exampleJones, E. (2013) Back To The Future: Developing Competent Services For People With Intellectual Disabilities And Challenging Behaviour, Advances in Mental Health and Intellectual Disabilities Vol. 7: 1 pp. 5 - 17Brown,M, James, E. and Hatton, C (2017) A Trade in People: The inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder Lancaster: Centre for Disability Research. |
|  108 | Foundation for People with Learning Disabilities | Key area for quality improvement 4 | Recommendations for local authorities, clinical commissioning groups and service providers. | Extend this quality standard to include working with housing and service providers that would offer bespoke support that is created in line with the individuals person centred plan and needs.Security of tenure being paramount as if things go wrong then the person is not penalised and being moved but corrective practice is built at the source. The person is not at fault or is not the problem the intervention did not work. | Environmental factors and person centred planning important if we are to avoid https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdfavoid inpatient services take the support to the person. |
|  109 | Hertfordshire Partnership University NHS Foundation Trust (HPFT) | Key area for quality improvement 4People with learning disabilities and behaviour that challenges should have a range of housing options available that meet their needs and cater for different preferences and person centred support needs. | A good range of local housing and care options increases the robustness of community service provision in a geographical area and reduces the need for out-of-area options to be sought. It also increases the likelihood that people can be supported in a model of their choice in an area of their choice.A poor range of local options may result in extended stays in inpatient services, potentially resulting in a further deterioration of mental health. | Currently, a lack of housing options often prevents people being able to live in area of their choice, which can mean people living outside of an area where they have social connections and links. Additionally, a lack of housing and care options is seen locally to have a major impact on delayed discharge from inpatient assessment & treatment settings. |  |
|  110 | Mencap | Better environments to support people’s wants and needs | Providing the right environments for people to live in. This needs to be more person centred not always based simply on cost. This goes for new tenders as well as existing services where people are placed in services that don’t meet their needs.Support to access the right living environments based on environmental and functional assessments. | Perhaps not enough attention is paid to the environment, both the actual accommodation and locations. | Importance of the right environment in supporting people with a learning disability and behaviour that challenges is well-recognised eg. NHSE Building the Right Support- Service Model.  |
|  111 | Milestones Trust | Appropriate environments | Congregate settings and residential care are still commonplace even for people with very complex behaviours who find sharing space difficult. | Organisational will is paramount in driving this forwards, as is access to robust information/evidence regarding alternative models of service provision. This hampers conversations with commissioners and families. |   |
|  112 | NHS England, Local Government Association and Association of Directors of Adult Social Services joint response | **Housing and support for adults with learning disabilities and behaviour that challenges**  | There is good evidence about the impact of the built environment upon people living with a disability and a growing literature about how the right housing environment can increase independence and choice for people with a learning disability, autism or both. The principles of giving people choice about their living arrangements, including who they live with, and offering options for settled accommodation and increased security of tenure are about respecting the rights of people but are also critical principles to get right in improving quality of life for people. We know, for example, that individuals with complex and challenging behaviours often require tailored solutions that will minimise the triggers for behaviour, creating a safe and settled environment to live in.Separation of accommodation from support is also a critical principle. We know that in some cases, where the home is supplied by the support provider, individuals sometimes find themselves losing their home because the provider felt they could no longer support the person.  | There is a lot of variation in the way that housing and support is designed for people with a learning disability and no generally recognised Design Standards as there are for housing for older people.There is variation across the country in terms of the number of people with a learning disability who live in their own home or with their family. Data for 1G of the Adult Social Care Outcomes Framework 2016-17 showed that the proportion of adults aged 18-64 who received support with a primary learning disability need in a social care area who lived in their own home or with their family ranged from 33.2% to 100% of the total.One of the factors for people with a learning disability, autism or both being admitted to specialist hospital or readmitted following a discharge is the unsuitability of their housing. | Mental Health Services Dataset contains information about the care of children, young people and adults who are in contact with mental health, learning disability or autism services https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-setAdult Social Care Outcome Framework 2016-17 data:https://digital.nhs.uk/data-and-information/publications/clinical-indicators/adult-social-care-outcomes-framework-ascof/current/enhancing-quality-of-life-for-people-with-care-and-support-needs/1g-proportion-of-adults-with-a-learning-disability-who-live-in-their-own-home-or-with-their-familyReport of the Equality and Human Rights Commission into housing and disability 2018: https://www.equalityhumanrights.com/en/housing-and-disabled-people-britain%E2%80%99s-hidden-crisisBuilding the right home:https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2015/11/building-right-home-guidance-housing.pdf |
|  113 | People First | Good accessible housing is the first step in then making sure you can use services. Having an accessible and appropriate home is very important. When house builders build new homes those homes must be accessible to disabled people so that independent living becomes a reality not to dream or aspiration |
|  114 | SCM 2 | Housing options | NICE guidance recommends that adults with learning disabilities who have behaviour that challenges be offered the option to live alone with support if they prefer this and it is suitable. The Committee heard expert witness evidence on the importance of such individualised services. If adults prefer not to live alone with support, or it is not suitable for them, offer them the option of living with a small number of other people in shared housing that has a small-scale domestic feel. | Many adults do not get offered the choice to live alone with support. This limits the options to address the risk that highly vulnerable people are housed with people who place them at risk. It reduces the ability of services to provide highly individualised services where needed. There are many services to people with learning disabilities who have behaviour that challenge that are not small in scale or homely. There is concern amongst many practitioners, families and academics about a potential trend to recreate the larger and more institutional settings of the past. | [NHS England, ADASS and LGA (2015) Building the Right Support: Service Model states (at 5.1) “People should be offered a choice of housing, including small-scale supported living. This choice may be circumscribed by the Ministry of Justice (MOJ) in some instances if the individual is on an offender pathway. Choice about housing should be offered early in any planning processes (e.g. in transition from childhood to adulthood, or in hospital discharge planning) and should be based on individual need and be an integral component of a person’s person-centred care and support plan (see principle 2). Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective and at the outset of planning”.](https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf) |
|  115 | SCM 4 | Choosing where to live | ‘It is vital that people are able to choose where they live if there is an offer within the guide to support people to live in a place of their choice and with whom they want (a home ) not service...my own keys..! that meet people‘s needs and they have the right people to support them grow..and live with people if the chooses to and these people are compatible.’  |
|  116 | SCM 7 | Choosing where to live | It’s a common sense one…giving people choice of where to live. I also chose it as it refers to the importance of being close to home that you know- close to family (if that’s what the person wants….choice should be overall.) And I liked that it referred to these places being available for the shortest time necessary- that they are not an institution. People should have the support they need. |
|  117 | SCM 8 | Housing and emergency accommodation  | As a social care provider it is not uncommon to hear about people who need accommodation and support at short notice for a variety of reasons. Having skilled support staff available is difficult but not as resource heavy as maintain empty units of accommodation. We need to ensure that we are using the data and information we have about people to plan housing needs in advance. Many people can live in mainstream housing with just a few changes, many people can share accommodation if this is managed and people are supported well, a few people will need purpose built bespoke accommodation. The natural planning of housing can take years and as such we should not be waiting until someone is ready for discharge before we look at their housing needs as is often the case now. In an emergency there has been examples of third sector organisation working together to pull together teams of staff however finding a building/house from which to deliver the support has been challenging. No one can afford to keep housing empty. However the use of respite model in any new build developments could provide a solution. Emergency respite for people with complex needs would certainly prevent hospital admissions and is likely to ensure that families can stay together for longer.  |
|  118 | Three Cs Support | 1.5 Housing and related support. New and existing housing strategies should be reviewed in line with these guidelines.  |
| **4.6 Short break services**  |
|  119 | Hertfordshire Partnership University NHS Foundation Trust (HPFT) | Key area for quality improvement 5Short breaks should be available based on need, and at short notice both in crisis and to prevent a crisis. Short breaks should be tailored to the needs of the person and their family or carers, taking into account the person’s interests and preferences.  | Short breaks have important benefits for both the person with a learning disability and behaviours that challenge and their carers.Breaks from stressful environments may ultimately improve resilience and help carers to be able to cope better in the longer-term with support challenges they encounter. | This area of priority was seen as linked to preventing admissions and improving the robustness of community services and viewed as a current significant gap in service provision. The importance of short break services being able to deliver on any agreed guidelines or support plans while a person is in that setting is also a key need. |   |
|  120 | Three Cs Support | 2. Creative approaches to respite. For example, providers giving emergency support to a person in their own home rather than a residential centre. Setting up community support packages for people in crisis which have additional funding at the start of the package, which is then tapered off as the person settles. |
| **4.7 Inpatient services**  |
|  121 | OLM Group | Positive risk assessment and risk management to be carried out and reviewed at least every six months.These should encompass risks with families and carers. | Positive risk assessments enhance the persons wellbeing and opportunities. It allows for proactive approaches to be implemented and identified to put in place the least restrictive support for the person. People will be supported to stay out of trouble as identified in principle 8 of the NHS England 2017 developing support and services for children / young people with learning disabilities or both.Improvement to moving out of long-term hospital stays and institutional stays can be planned effectively.  | The NHS Digital 2018 statistics identify that there has been an improvement in the amount of people having long term stays as inpatients there are still at least half of people with no planned date to leave. | NHS Digital 2018 Learning Disability Service Statistics. |
|  122 | SCM 5 | When admitted to hospital there is a clear multi-agency outcome-based treatment plan with a focus in community reintegration | Treatment plans are still often medically focused with no mindedness for what needs to be in place to change community access by linking treatment to the crisis in the community to inform future plans. | Treatment outcomes are still vague, and disconnected from community life at CTRs. | Sorry haven’t been able to find the evidence bases at short notice – some may be in AT data collection, CTR outcomes and pull much of this out of the NICE guidelines for LD and behaviour that challenges. |
|  123 | SCM 7 | Going to hospital | Really liked this one. It should be the last point of call. It want it to help people think twice about this. Again, I like the element of being close to home, having a named worker and the plan to be checked every 3 months. |
|  124 | SCM 8 | Leaving hospital  | This fits neatly with all of the above. The discharge process for people feels largely reactive. We should (and are advised) to start planning for discharge as soon as one is admitted to hospital. This would allow for the families involvement, longer term commission and concentre plans for housing. Discharge should be expected and the culture for everyone, there are very few people with learning disabilities and additional behaviours that challenge that cannot be supported in their community. Research tells us that people are safe, family contact maintained and that they have a better quality of life. Whilst longer term costs are difficult to compare it is easier to argue value for money.  |
|  125 | SCM 9 | Quality of care provision for people with Learning Disability and Autism being discharged from secure hospitals | Transforming Care programme is reaching a critical point, with the programme scheduled to end in March 2019. Numbers in secure accommodation remain at similar levels despite a lot of effort. Consistently high quality of care needed to increase confidence of RCs and to reduce readmissions. | Quality of care for this specific service user group is not always of a good enough quality to be able to withstand the challenges of supporting people with complex needs and who present significant challenges | Anecdotal evidence locally – MDTs consistently expressing doubts about care providers' ability to manage and steering people's discharges away from supported living model espoused in Better Care (2015) towards specialist residential care, which is not in line with bringing people back home, care in the community, etc |
|  126 | SCM 9 | Social Work and Community Nurse Training to be able to better manage the complexities surrounding discharges from secure hospital and the prevention of admissions | Community Teams play a vital role in both effecting discharges and preventing admissions | There appears to be a variation in the speed and quality of social workers' and community nurses' responses to the different complexities involved in discharges. Ability of professionals to respond in a timely manner to deepening crises may be affected by workload and poor interagency communication. | Local observations – analysis of admissions that a significant percentage could have been prevented. Evidence of different professionals consistently advocating solutions that demonstrate a lack of understanding of what is proposed in Better Care (2015). |
| **4.8 Additional areas** |
| **Staff training** |
|  127 | Abertawe Bro Morgannwg University Health Board | Key area for quality improvement 4Emphasis should be placed on support providers implementing Practice leadership and Active Support | Practice leadership is increasingly recognised as a key feature of quality services, particularly related to the implementation of good practice. PBS competence framework reflects this and directly refers to practice leadership.Active support is part of the PBS framework and increasingly recognised as a key indicator of quality life | Practice leadership is key to effective implenetation of service modelsImproving quality of life is a key desired outcomeThere is considerable evidence that they help achieve quality of life outcomes and reflect service quality and competence issues | [http://pbsacademy.org.uk/pbs-competence-framework/http://www.bild.org.uk/capbs/capbswebinarssee for exampleBigby, C., & Beadle Brown, J., (2018) Improving Quality of Life Outcomes In Supported Accommodation For People With Intellectual Disability : What Makes The Difference, Journal of Applied Research in Intellectual Disabilities, 31 e182-e200Flynn S., Totsika, V., Hastings, RP, Hood, K., Toogood, S., & Felce, D. (2018). Effectiveness of Active Support for adults with intellectual disability in residential settings: Systematic review and meta-analysis. Journal of Applied Research in Intellectual DisabilitiesJones. E., Lowe, K., Brown, S., Albert, L., Saunders, C., Haake, N., Leigh, H. (2013) Active Support as a Primary Prevention Strategy for Challenging Behaviour International Journal of Positive Behavioural Support, Vol 3,1, 16-30](http://pbsacademy.org.uk/pbs-competence-framework/) |
| 128 | British Association of Social Workers | Key area for quality improvement 5Professionals working with adults who have learning disabilities and display challenging behaviour should receive specialist training and good quality supervision. | Social workers need to receive skilled and specialist training in line with their continuing professional development to enhance their social work practice.  | Social workers should be equipped with appropriate training and learning opportunities to inform their practice in addition to learning from colleagues and experience.  | BASW in partnership with RiPfA are currently developing a continuing professional development pathway and competency statements for social workers at each stage of their development.  |
|  129 | British Institute of Learning Disabilities | Need for a whole organisation approach to provision of PBS. | PBS cannot be implemented effectively in an individual service by staff attending a PBS training course. PBS needs an organisational approach because in addition to ensuring that support workers are skilled, empathic and in a good state of rapport with people with LD and challenging behaviour and that there are sufficient Practice Leaders available to these staff to ensure quality of practice and to provide them with support, there needs to be organisational systems, processes and structures to support implementation of PBS. | Implementing PBS needs a congruency throughout an organisation with staff at all levels understanding what PBS involves and what part they need to play. Organisations should ensure staff understand and use Active Support as a primary strategy in the prevention of challenging behaviour, with Practice Leaders ensuring they have the skills necessary. There also needs to be governance of practice with the most senior people being responsible for the practice of support workers as well as being responsible for their practical and emotional support when at work, supporting people with LD and challenging behaviour. |   |
|  130 | British Institute of Learning Disabilities | Psychology and/or behavioual support with expertise in Positive Behaviour Support (PBS) including Functional Assessment in community teams. | Services need access to behavioural expertise in order to provide support for people with learning disabilities and challenging behaviour (Allen et al 2013). Many provider organisations do not have this expertise ‘in-house’ and rely on community teams for this expertise. Our experience is that the understanding of what PBS is and what implementation involves in community teams varies widely. | Behaviour Support Plans need to be based on Functional Assessment to ensure that strategies and interventions are appropriate and will not reinforce challenging behaviour.Not all psychologists are trained to or experienced in completing Functional Assessments and those that are often have waiting lists or caseloads which mean that full assessment is not possible. Skilling up members of the service provider workforce to contribute to Functional Assessments, with the oversight of an expert with relevant experience and qualification would greatly help the situation. |   |
|  131 | British Institute of Learning Disabilities | Staff recruitment, retention, Practice Leadership and a career pathway. | There is increasing evidence that support for people with LD and challenging behaviour is best provided by staff who know the person well, have a good relationship and state of rapport with them and that the quality of this rapport and support is a variable in the occurrence and non-occurrence of challenging behaviour. People with LD and challenging behaviour have also described the quality of relationships with their staff as important. Good staff need to be supported by services to stay with their service users for more than the short term. To do this they need to feel fulfilled in their job, competent, confident and with their emotional support needs taken care of by their service. | Staff need support from Practice Leaders in order to be able to support people with LD and challenging behaviour long-term. Organisations explicitly valuing Practice Leaders by ensuring there are sufficient Practice Leaders available for staff with sufficient time to provide the practice leadership function would improve the ability of staff to do a difficult job. A career path from support worker to Practice Leader (rather than the only promotion otherwise being to that of a manager) would make it more likely that good staff stayed and that support workers were supported by good Practice Leaders. |   |
|  132 | The Challenging Behaviour Foundation | Specialist skills for the workforce  | People with learning disabilities face a wide range of issues. To meet these needs effectively, staff working with people with learning disabilities and behaviours that challenge need to be appropriately skilled. | There is much evidence indicating that the care of people with severe learning disabilities and behaviours that challenge is currently inadequate. Despite the national transforming care programme recognising that people with learning disabilities and behaviours that challenge should be able to get the right support in the community, this is not being provided. Individuals with learning disabilities and behaviour perceived as challenging are likely to:Live in places or with people they don’t like, often a long way from their family home.Be given too much medication, or inappropriate medicationBe subjected to restraint.Be secluded and have their movement restricted.Many people with a learning disability have ended up in an inpatient unit due to a failure to provide or develop the right support and services in the local community. At the end of January 2018 there were 2,465 people with a learning disability in inpatient services. This issue is a finding of the 2017 National Audit Office report which concluded that there is a lack of a workforce with the right skills to support people with learning disabilities in the community.  |   |
|  133 | Foundation for People with Learning Disabilities |  Key area for quality improvement 5 | As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support the children, young people and adults they are working with. This includes.Ensuring that staff bring with them the correct values and understanding of the social model of disabilities. their training should be about the one person they are to support .  | For this to become effective it requires staff engaged with the person in mind and in line with their person centred plan.Training should be based on full understanding of the person and who they are. Not with negative reinforcement of how they react if their support is not appropriate.We know what good support looks like let’s make it common practice. | [https://www.gettalifeonline.co.uk/https://www.cqc.org.uk/provider/1-101719666see Gettalife in Coventrythey support people to live the life they choose based on their person centred plan, this might include;Attending college or church, participating in theatre.Getting involved in the community, being a community teacher, volunteering or contributing to other peoples well being,Going shopping, Participating in the day to day activities in their homes like cooking and cleaning.Horse riding, sailing, ice skating, football.More importantly we support people to build meaningful relationships and connections. This takes time. Some people have to relearn how to trust and heal from past hurts before they can start to develop relationships.](https://www.gettalifeonline.co.uk/) |
|  134 | Mencap | Sector wide understanding of what Positive Behavioural Support is | A clearer understanding of what makes a PBS service (and what defines a person as requiring a PBS service). A sector wide commitment to PBS as the way of supporting people and a rejection of application of behavioural models that use aversive practice.Support to ensure that Quality standards are evaluated based on the practice of the people supporting, not based on the processes that they have in place.Adoption by CQC/regulators into KLOEs of clear guidelines on what makes a PBS service.An adoption of the standards that describe the Staff skills and values and training needed to deliver a PBS service. |   |   |
|  135 | OLM Group | Additional developmental areas of emergent practiceStaff training around PBS and risk assessments needs to be improved. Further training strategies are also required for carers and families of people with LD and Autism to promote a better understanding and proactive approaches.  | Consistent training for PBS will result in a more rounded approach towards the PBS. This will improve the wellbeing for the person and their carers and reduce crisis situations from developing. Family breakdown would be reduced and clear training pathways would impact the cost of caring for people who would otherwise have been placed in long term residential care. There will be a reduction in injuries and an increase in opportunities for the person. | Currently the training for PBS is based around care providers understanding of what PBS is. For families and carers in the community training is difficult to find which leads to inconsistent approaches between them and other people supporting the person. Linked working is affected where consistent training paths that are properly assessed are not in place.The NMDS adult social care workforce estimates that only 11% of staff have received training in positive behaviour support and control and restraint. Only 6% have received training in learning disability. | Skills for care workforce intelligence – The state of the adult social care sector and workforce in England September 2017 |
|  136 | PBS4 | Key area for quality improvement 1Positive Behaviour Support delivery is underpinned by Applied Behaviour Analysis and is overseen clinically by a registered/certified professional with recognised qualifications in Applied Behaviour Analysis. | There is evidence that training in PBS for frontline staff is not enough. There is evidence that there are a large number of professionals in “PBS practitioner” or similar positions are not registered/certified and there is therefore no guarantee what level of training and supervision they have had and they are not accountable to a professional body or work to a code of conduct. The lack of professionalism in PBS puts the approach at risk of poor reputation due to misapplication. It is not fair for people with learning disabilities to receive interventions by people not trained properly to implement this and it would not be accepted in any other arena. There are large clinical risks when implementing behavioural interventions and those without appropriate qualifications and registrations may not be aware of these or practice in a way that mitigates this risk. | I don’t understand the difference in this column and the previous. | PBS Academy PBS Core Competency FrameworkHassiotis study on PBS training published this year.BACB Code of ConductNMC Code of ConductBeebee, Martin, Wooldridge, 2015 “Who are PBS Practitioners in the UK” https://positivebehavioursupport.wordpress.com/2015/07/21/who-are-behaviour-practitioners-in-the-uk/ Currently being expanded internationally |
|  137 | Royal College of Paediatrics and Child Health | **Key area for quality improvement 3Training programmes and sources of advice for professionals in Learning Disability assessment and work**  |   | There is good practice and practical principles but very few training programmes  |   |
|  138 | Royal College of Psychiatrists | Key area for quality improvement 1There should be appropriate LD/ASD specific skills, knowledge and experience in CYP inpatient provisions offering care to this group (being local to home is not enough, if the staff/environment are not the right fit). |
|  139 | Royal College of Psychiatrists | Key area for quality improvement 3Behaviour support practitioners should be appropriately trained in evidence based approaches to the management of challenging behaviour eg PBS, ABA, modified parenting programmes eg incredible years, triple P etc. There is a growing evidence base in this area, to improve outcomes for these young people. |
|  140 | Royal College of Psychiatrists | Key area for quality improvement 8There should be appropriate LD/ASD specific skills, knowledge and experience in adult (LD and general adult) inpatient provisions offering care to this group |
|  141 | Royal College of Psychiatrists | Key area for quality improvement 10Behaviour support practitioners should be appropriately trained in evidence based approaches to the management of challenging behaviour eg PBS, ABA, etc |
|  142 | Skills for Care | A clear quality measure for PBS training | This does not exist, so contracts and training are not based on any standards | The quality of the skills and undertraining of staff at all levels largely defines the quality of life for the key group.  |   |
|  143 | SCM 1 | Key area for quality improvement 5 | Workforce recruitment, training, skills and retention to support children and adults with learning disabilities who display behaviour described as challenging is addressed through a strategic plan, linked to population requirements |   | NAO report (2017) and recommendations – highlighted the lack of workforce strategy and the need to address this urgently |
|  144 | SCM 6 | The provision, uptake and implementation of Positive Behavioural Support.  | In order to ensure people with learning disabilities and behaviour that challenges receive the most appropriate and effective support to meet their needs, Positive Behaviour Support significantly assists in enabling staff to understand and respond to people in a consist and personalised way.  | In supporting people with learning disabilities and behaviour that challenges, as evidence attests, Positive Behaviour Support is effective in successfully reducing/redirecting challenging behaviours. By ensuring this approach is widely adopted and applied correctly, has the fundamental benefit of helping to improve care delivery. | An array of contemporary guidance exists to illustrate effective outcomes when Positive Behaviour Support: https://www.skillsforcare.org.uk/Topics/Learning-disability/Positive-behavioural-support/Positive-behaviour-support.aspxhttps://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2016/07/bild-key-questions.pdfhttps://www.hee.nhs.uk/sites/default/files/documents/The%20key%20messages%20about%20Positive%20Behaviour%20Support\_0.pdf |
|  145 | SCM 6 | Enhancing competence in the application of least restrictive approaches.  | The numbers of people with learning disability and behaviour that challenges subject to detention under the mental health act continues to increase. By exploring and deploying new/creative lesser restrictive approaches within people’s usual environments it should influence use of the MHA.  | The continuum of support and intervention for people with learning disabilities and behaviour that challenges is made up of multiple elements. At the reactive/emergency end, professionals working in the community needs to consider how they can initiate alternatives options at the point of assessment for detention. We know the success of this branch of work when enacted effectively has a positive impact on the longer-term experience/quality/outcomes from people and their families.  | [https://www.skillsforcare.org.uk/Document-library/Skills/People-whose-behaviour-challenges/Positive-Behavioural-Support-Competence-Framework.pdfwww.northumbriajournals.co.uk/index.php/IJMHMCL/article/download/551/948https://www.cqc.org.uk/publications/themed-work/mental-health-act-restrictive-intervention-reduction-programmes](https://www.skillsforcare.org.uk/Document-library/Skills/People-whose-behaviour-challenges/Positive-Behavioural-Support-Competence-Framework.pdf) |
|  146 | SCM 4 | Staff skills and training | The workforce and skill set of the workforce is key as these are the people that hold the power.So if they don’t get it it’s not going to work as power in these systems are not bottom up are top down, I feel with the right ....Training and recruitment, retention and competency everything is possibleI. Value based practice that puts people at the centre of staffs values and working ways. |
|  147 | SCM 5 | Supporters have training, supervision and support in sensory& communication problems and PBS | To reduce challenging behaviour and deliver effective care and support re: page 15,17,19, 35 of guideline | Significant gaps in training for the workforce in this area everywhere I go in CTRs, TCP –  | Sorry haven’t been able to find the evidence bases at short notice – some may be in AT data collection, CTR outcomes and pull much of this out of the NICE guidelines for LD and behaviour that challenges. |
| **Functional assessment and positive behaviour support plans** |
|  148 | Abertawe Bro Morgannwg University Health Board | Key area for quality improvement 1 Direct reference to Positive Behavioural Support (PBS) framework, and the more explicit use of the term PBS throughout the guidance -- such as defining the term in the glossary and use of the term within the recommendations | Many of the recommendations reflect the PBS framework (see for example Gore et al (2013) Definition and Scope for Positive Behaviour Support. International Journal of Positive Behavioural Support 3(2), 14-23, Hastings et al., (2013) ‘A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities’, International Journal of Positive Behavioural Support, 3(2), 5–13.)There is an increased interest, understanding and development of good practice that falls within the PBS framework, throughout the UK and internationally.  | Direct use of the term PBS within the recommendations would greatly assist in the implementation of the guidance by building on developing good practice. This is shown to some degree in the research studies and expert witness testimonies included in the evidence section. However, emerging good practice in PBS is under-represented in the guidance as it currently stands. The inclusion of examples of good PBS practice in the final version would greatly assist with implementation and the aim of improving the quality of life of people, their families and carers. It is often the family members and staff in closest contact with the person with LD who suffer the greatest stress and need to have the clearest understanding of the terminology associated with good practice. Indeed families and advocates need to have a vocabulary to articulate what they want from service providers and commissioner and for there to be a shared understanding of what this entails. The increased use of the term Positive Behavioural Support would considerably assist this | (See for exampleChallenging Behaviour Foundation http://www.challengingbehaviour.org.uk/PBS academy http://pbsacademy.org.uk/ ,British Institute of Learning Disabilities, http://www.bild.org.uk/our-services/positive-behaviour-support/capbs/  |
|  149 | Milestones Trust | PBS | Everyone with complex behavioural needs should have an up to date PBS plan which is a live document and updated regularly, be supported by appropriately trained staff, and organisations should have effective data collection methods to inform functional analysis. | National standards (driven by the PBS Academy) are not yet widely understood, there is no nationally recognised accreditation scheme for providers, and sharing information and best practice is seen as problematic by competing providers. Workforce recruitment, retention and development is critical. | [Locally, the work of the Avon PBS network has been invaluable in offering training, support and networking opportunities: https://positivebehaviour.wordpress.com/](https://positivebehaviour.wordpress.com/)  |
|  150 | OLM Group | A full systematic, functional, contextual and skills based assessment should take place. This should be an assessment that starts during early years when behaviours have been identified and continues linked together through their lives.It should be carried out with the person not for them and involve linked working between the person, schools, LA’s and care providers where necessary. | The evidence suggests that there has been a decrease in children being excluded from school and the increase in assessments completed separately or joint with the client. There is also an increase to people’s wellbeing and avoiding contact with criminal justice.Identifying early on the reasons for behaviours, etc. allows for proactive behaviour support plans and positive behaviour support to be implemented and carried through.  | The PBS competence framework has found claims of PBS being implemented across providers, etc. in reality bear no resemblance to the PBS framework. The approach is currently disjointed and several assessments could take place by different teams that have not taken into account assessments carried out by different teams. This leads to assessments and goals not being linked togetherNHS England 2017 Developing Support and Services for Children and Young People with Learning Disabilities, Autism or both identifies that delayed assessment and diagnosis results in behaviours, family breakdown and increase in hospital admissions. | NHS digital 2018 learning disability statistics.Transforming care service model specification 2017People with learning disability in England 2015 data tables.These highlight the statistics for people with learning disabilities and autism alongside the statistics for assessments carried out, and exclusions from schools. |
|  151 | PBS4 | Key area for quality improvement 3Positive Behaviour Support plans are based upon meeting functions of challenging behaviour, not just reducing behaviours that challenge others. A full functional behaviour assessment is completed by a registered/certified professional with appropriate qualifications for behaviours that have not reduced in 3 months. Function based plans are then developed from these functional based assessments.  | There are many PBS plans that still focus on behaviour reduction despite a functional assessment being in place. This moves away from the key difference in PBS compared to other behavioural interventions.  |   | Gore et al, 2013, Definition and scope of PBS, International Journal of PBS.PBS Academy PBS Core Competency Framework |
| **Medication** |
|  152 | Royal College of Paediatrics and Child Health | **Key area for quality improvement 5The use of psycho active medication: parameters, such as guidance, are only part of a wider assessment and management, between all the clinician responsibilities and reviews etc.**  | Medication in these circumstances are still greatly over used, especially major anti psychotics e.g. Risperidone, in isolation from behavioural assessment and management, multiple drugs are often added on, and there can be limited expertise or consultation etc.  | There is a misuse of major medication There can be a lack of boundaries – there are many examples of over-prescription to children by individual clinicians in private and NHS practice  | Including unchecked concerning use of medication by some Tertiary centres e.g. Evelina |
| **Identification of learning disabilities and terminology used** |
|  153 | Royal College of Paediatrics and Child Health | **Key area for quality improvement 7There are only a proportion of children and people with Learning Disabilities known to services and on Learning Disability registers** | Only a minority of people with Learning Disabilities are known to services – e.g. only around quarter of people with Learning Disabilities are currently on Learning Disability registers and only about half of them receive annual health checks. Not recognising that somebody has a Learning Disability will make them even more vulnerable including vulnerability to being incarcerated (criminal justice system), vulnerability to radicalisation and gangs. Different terms are frequently used instead of the term Learning Disability: e.g. there could be education on the use of the term Learning Difficulty or even Developmental Delay instead of Learning Disabilities | So that early prevention and intervention could be put in place on time, early diagnosis and early enrolment in Learning Disabilities registers of Learning Disabilities is the key.  | People with Learning Disabilities in England 2015 Improving Health and Lives: Learning Disability Observatory |
|  154 | Royal College of Paediatrics and Child Health | **Key area for quality improvement 8Different terms are frequently used instead of the term Learning Disability: e.g. education use the term Learning Difficulties or even Developmental Delay instead of Learning Disabilities** | Learning Disabilities will make them even more vulnerable including vulnerability to being incarcerated (criminal justice system), vulnerability to radicalisation and gangs.If a child or young person has mild or borderline Learning Disabilities they may never be recognised as having Learning Disabilities but may be in and out of prison for years.Early recognition would be supported if the same terminology is used by Education and Health. | Education and Local Educational Authorities so that people with Learning Disabilities are early recognised. Education could inform the Learning Disability registers. | Deborah Shelton, A Study of Young Offenders with Learning Disabilities, Journal of Correctional Health Care, 2006 |
|  155 | OLM Group | Transition plans from one service to another including from childhood services to adult services should be linked.Transition champions in organisations to improve transitions are required. | There is evidence to suggest that transition plans prevent delayed assessments and moving from one service to another.They also prevent placements from breaking down which could increase the frustrations for the person.A full transition plan puts the person in control of their support and needs and allows services to prepare the environment and staff to meet the needs of the person. This includes provisions in the community. Needs are identified and acted on which promote high quality care and proactive approaches. | The challenging behaviour Explains that transitions can be complicated and cause anxiety. A study undertaken by TIN found that over three years satisfaction with services had decreased. |   |
| **Transition from children’s to adult services** |
|  156 | Royal College of Psychiatrists | Key area for quality improvement 5Transition arrangements for CYP with LD to adult services should be tailored in duration and style to the CYP and monitored (including for out of area placements) starting before 18. Each CYP is different in their needs, blanket arrangements are not appropriate for this group. |
|  157 | Royal College of Psychiatrists | Key area for quality improvement 11Transition arrangements for CYP with LD to adult services should be tailored in duration and style to the CYP and monitored (including for out of area placements). Potentially continuing beyond 18 if indicated. |
|  158 | Three Cs Support | There is no guidance on how the transition from CYP services to adult services should be managed. |

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