NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

**Quality standard topic:** Challenging behavior and learning disabilities

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

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# Contents

[1 Introduction 2](#_Toc365024201)

[2 Overview 2](#_Toc365024202)

[3 Summary of suggestions 9](#_Toc365024203)

[4 Suggested improvement areas 11](#_Toc365024204)

[Appendix 1:](#_Toc365024205) [Suggestions from stakeholder engagement exercise](#_Toc365024208) 36

1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for Challenging behaviour and learning disabilities. 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:

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE clinical guideline CGXX (in development)

1. Overview
   1. Focus of quality standard

This quality standard will cover the care of adults, children and young people with learning disabilities and behaviour that challenges.

* 1. Definition

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, and onset in childhood. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. Although the term ‘intellectual disability’ is becoming accepted internationally, ‘learning disability’ is the most widely used and accepted term in the UK and is therefore used in this quality standard, in line with the source guidance.

Some people with learning disabilities display behaviour that challenges. ‘Behaviour that challenges’ is not a diagnosis and is used in this quality standard to indicate that while such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability. This behaviour often results from the interaction between individual and environmental factors and includes aggression, self-injury, stereotypic behaviour, 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

The question of prevalence has been subject to a range of methodological approaches and consequently there has been a variety of differing figures presented in relevant papers. Studies that use inpatient units as the setting may produce higher figures as the environment may exacerbate the behaviour. Also, some studies count only a single behaviour, whilst others identify several behaviours and many studies estimate prevalence by asking carers and families. The NICE guideline references a generally accepted range for prevalence of behaviour that challenges as approximately 6 to 14% of people with a learning disability who are known to services. These figures derive from surveys of total populations of people with a learning disability (administratively defined) and include all types of behaviour that challenges. In 2013 a Public Heath England report estimated that there were 1,068,000 people with learning disabilities, using data on those in contact with services[[1]](#footnote-1). This was broken down into 900,900 adults and 224, 930 children. The Mental Health and Learning Disabilities Statistics monthly report for September 2014 showed that there were 46,473 people in contact with learning disability services across England[[2]](#footnote-2). A more recent paper estimating the number of children in England with learning disabilities and challenging behaviour put the figure of those aged between 0-18 at 41,547 children in 2014[[3]](#footnote-3).

In the NICE guideline prevalence rates for behaviour that challenges in people with a learning disability are estimated at around 5-15% in educational, health or social care services. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30-40% in hospital settings). It should also be noted that behaviour that challenges may be more likely in people who have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems.

The same behaviour may be considered challenging in some settings or cultures, but not in others and may appear in only certain environments. Some care environments increase the likelihood of behaviour that challenges. These include those with limited social interaction and meaningful occupation, lack of choice and sensory input or excessive noise, those that are crowded, unresponsive or unpredictable, and those characterised by neglect and abuse. Challenging behaviour may be used by the person for reasons such as creating sensory stimulation.

* 1. Management

Services for children, young people and adults with a learning disability and behaviour that challenges have been described as fragmented and at times ineffective and unresponsive to family needs, to the point sometimes of being abusive (Mencap, 2013)[[4]](#footnote-4). For children and young people services are generally provided within education (through their school and the educational psychology service), as well as through generic child and adolescent mental health services (CAMHS). Families report that they experience a number of unrelated services and that many will offer no help. Moreover, there are very few early intervention services routinely available for children with a learning disability.

For adults, care is often managed through a community learning disability team (CLDTs), which includes a range of professionals, typically learning disability nurses, psychologists, psychiatrists, occupational therapists, physiotherapists and speech and language therapists. Social workers are also co-located and integrated into the CLDT in many areas. However, in some areas they are located at separate social services offices. For adults with a learning disability and behaviour that challenges, day services, or the residential/supported living service may try to support them initially. If behaviour that challenges continues, they may refer people to the CLDT and their families may also access the CLDT through the local GP or other agencies.

However, the experience of carers has often been that there is insufficient support from professionals, who do not have the required expertise and do not provide help early enough (Griffith & Hastings, 2013)[[5]](#footnote-5). The failure of services or families not being able to cope is likely to lead to over-medication of the individual with a learning disability, disengagement by professionals, and eventually ‘out of area’ placements, which are often located away from families, some with restrictive practices and very high costs. It is estimated in the NICE guideline that many ‘assessment and treatment’ units cost in the region of £250,000 per 30 person per year.

Winterbourne View demonstrated the dislocation and poor quality of services that are experienced by children, young people and adults with a learning disability whose behaviour challenges and highlighted the restrictive practices used and lack of positive assessment or intervention.

There have been a number of quality improvement initiatives in response to Winterbourne View including the development of a Core Principles Commissioning Tool to be used to create local specifications for services supporting children, young people, adults and older people with a learning disability and / or autism who display or are at risk of displaying behaviour that challenges. In addition a national Learning Disabilities Mortality Review Programme has been commissioned by NHS England to identify variation and best practice and assess the impact of service change leading to the identification of key recommendations for improvement. This is due to begin in May 2015.

However, recent data indicates that the key target of the post Winterbourne View concordat agreement to have transferred all people, for whom it was appropriate, from mental health hospitals into the community by June 2014, has not yet been met (National Audit Office, 2015)[[6]](#footnote-6). The snapshot data of the Learning Disabilities Census for 2014 showed that on the 30th September 2014 there were 2,600 people with learning disabilities in inpatient mental health units. 920 of these had no date for planned transfer to the community[[7]](#footnote-7).

* 1. National Outcome Frameworks

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

### Table 1 [NHS Outcomes Framework 2015–16](https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016)

|  |  |
| --- | --- |
| **Domain** | **Overarching indicators and improvement areas** |
| 2 Enhancing quality of life for people with long‑term conditions | ***Overarching indicator***  2 Health‑related quality of life for people with long‑term conditions\*\*  ***Improvement areas***  **Ensuring people feel supported to manage their condition**  2.1 Proportion of people feeling supported to manage their condition\*\*  **Enhancing quality of life for carers**  2.4 Health-related quality of life for carers |
| 4 Ensuring that people have a positive experience of care | **Improving hospitals’ responsiveness to personal needs**  4.2 Responsiveness to in-patients’ personal needs  **Improving children and young people’s experience of healthcare**  4.8 Children and young people’s experience of inpatient services |
| 5 Treating and caring for people in a safe environment and protecting them from avoidable harm | ***Overarching indicators***  5a Patient safety incidents reported  5b Safety incidents involving severe harm or death  5c Hospital deaths attributable to problems in care |
| **Alignment across the health and social care system**  \*\* Indicator is complementary | |

### Table 2 [The Adult Social Care Outcomes Framework 2015–16](https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-2015-to-2016)

|  |  |
| --- | --- |
| **Domain** | **Overarching and outcome measures** |
| 1 Enhancing quality of life for people with care and support needs | ***Overarching measure***  1A Social care‑related quality of life\*  ***Outcome measures***  **People manage their own support as much as they wish, so that are in control of what, how and when support is delivered to match their needs.**  1B Proportion of people who use services who have control over their daily life  1C Proportion of people using social care who receive self‑directed support, and those receiving direct payments  **Carers can balance their caring roles and maintain their desired quality of life.**  1D Carer‑reported quality of life |
| 2 Delaying and reducing the need for care and support | ***Overarching measure***  2A Permanent admissions to residential and nursing care homes, per 100,000 population  ***Outcome measures***  **When people develop care needs, the support they receive takes place in the most appropriate setting and enables them to regain their independence**  2C. Delayed transfers of care from hospital, and those which are attributable to adult social care |
| 3 Ensuring that people have a positive experience of care and support | ***Overarching measure***  **People who use social care and their carers are satisfied with their experience of care and support services**  3A. Overall satisfaction of people who use services with their care and support  3B. Overall satisfaction of carers with social services  ***Outcome Measures***  **Carers feel that they are respected as equal partners throughout the care process**  3C. The proportion of carers who report that they have been included or consulted in discussions about the person they care for  **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help**  3D. The proportion of people who use services and carers who find it easy to find information about support  **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual** |
| 4 Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm | ***Overarching measure***  4A. The proportion of people who use services who feel safe ***Outcome measures***  **Everyone enjoys physical activity and feels secure**  **People are free from physical and emotional abuse, harassment, neglect and self-harm People are protected as far as possible from avoidable harm, disease and injuries**  **People are supported to plan ahead and have the freedom to manage risks the way that they wish**  4B. The proportion of people who use services who say that those services have made them feel safe and secure |
| **Aligning across the health and care system**  \* Indicator complementary  \*\* Indicator shared | |

### Table 3 [Public health outcomes framework for England, 2013–2016](https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency)

|  |  |
| --- | --- |
| **Domain** | **Objectives and indicators** |
| 4 Healthcare public health and preventing premature mortality | ***Objective***  Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities  ***Indicators***  4.13 Health-related quality of life for older people (Placeholder) |

1. Summary of suggestions
   1. Responses

In total 5 stakeholders responded to the 2-week engagement exercise 29/12/14 – 9/02/15.

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 4 for further consideration by the Committee.

NHS England’s patient safety division did not submit any data for this topic.

Full details of all the suggestions provided are given in appendix 1 for information.

Table 4 Summary of suggested quality improvement areas

| **Suggested area for improvement** | **Stakeholders** |
| --- | --- |
| **Early intervention (0-5)**   * Early support and training for children, families and those who support children with learning disabilities. | SCMs |
| **Assessment**   * Timely and stepped assessment. * Comprehensive health assessments for children and young people who present with challenging behaviour. * Assessment of environmental impact on behaviour. * Inclusion of responsible risk taking in behaviour risk assessments. | RCPCH, ELDPBS, RCN, SCMs |
| **Interventions**   * Opportunities to engage in meaningful occupation or valued activity. * Use of person-centred positive behaviour support plans. * Clear documented risk assessment of reactive strategies with details of monitoring and review. | COT, ELDPBS, RCN, SCMs |
| **Medication**   * Ensure clear rationale for prescribing and shared decision making. * Appropriate monitoring and review. | CMHP, RCN, SCMs |
| **Family and Carer Support**   * Improved training and support in communication skills for people with learning and disabilities and their families and carers. * Training and support for families. | SCMs, ELDPBS |
| **Supporting infrastructure**   * Multi-disciplinary team composition. * Use of a named keyworker approach. | ELDPBS, RCPCH, RCN |
| **CAMHS services**   * Early and timely access to CAMHS services. | RCPCH |
| **Additional areas**   * Training and support for staff. * Use of the Health Equalities Framework developed by the Learning Disability Consultant Nurses Group. | RCN, ELDPBS, SCMs |
| CMHP, College of Mental Health Pharmacy  College of Occupational Therapists, COT  ELDPBS, Enfield Learning Disability Partnership Board Services  RCN, Royal College of Nursing  RCPCH, Royal College of Paediatrics and Child Health  SCM, Specialist Committee Member | |

1. Suggested improvement areas
   1. Early intervention (0-5 years)
      1. Summary of suggestions

**Early support and training with families and those who support children with learning disabilities.**

Stakeholders highlighted a need for quality improvement around the early intervention support provided for children with learning disabilities who are beginning to display behaviours described as challenging. It was suggested that this should include support and training for families and those who have a role in supporting children with learning disabilities. Stakeholders commented that there was currently no systematic approach to ensure that children and their families get the right support early and emphasised that a preventative approach was needed, intervening before the child had started to develop the challenging behaviour. It was suggested that although parents may have received psychoeducational parenting programmes, which is mainly based on mainstream children, they were less likely to have attended group training focussing on behaviour principles and development of communication. Responses highlighted that without early intervention challenging behaviours could become well established and impact on the efficacy of later treatment.

* + 1. Selected recommendations from development source

Table 5 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 5 to help inform the Committee’s discussion.

Table 5 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Early support and training with families and those who support children with learning disabilities. | NICE CGXX (in development) Research recommendation 2.1 |

NICE CGXX (in development) – Research recommendation 2.1

Preventing the development of behaviour that challenges in children aged under 5 years with a learning disability.

* + 1. Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience from local audit data.

* 1. Assessment
     1. Summary of suggestions

**Timely and stepped assessment**

Stakeholders commented that delays in assessment can increase the burden of care and be detrimental to the quality of life of the individual. It was reported that assessments could take up to three months to be completed and management plans for psychosocial interventions longer to implement, dependent on the availability of the support provider. Moreover, one stakeholder stated that audit data indicates that community learning disability services do not have arrangements for ensuring assessment and treatment is stepped with clear progression criteria. This results in duplication of effort and lengthy waiting lists.

**Ensure comprehensive health assessments for children and young people who present with challenging behaviour**

One stakeholder identified comprehensive health assessments as an area for improvement. Responses also specified that underlying physical health problems are often overlooked in assessment and remain untreated when they may be causing or exacerbating challenging behaviour. It was suggested that the normal assessment technique or investigation may require adaptations to ensure this is addressed.

**Assessment of environmental impact on behaviour**

Responses within the theme of assessment also included assessment of the individual’s environment. It was acknowledged that consideration of how an environment matches the individual’s needs and preferences was challenging when people share accommodation. However, it was suggested that the impact of the environment on behaviour should be assessed individually and should include the physical environment, the social environment, the sensory aspects of that environment, the human aspects (i.e. the people within the environment and their knowledge, beliefs and training), and the opportunities the environment offers a person.

**Inclusion of responsible risk taking in behaviour risk assessments**

Stakeholder responses also raised the issue that risk management strategies may limit the life opportunities if responsible risk taking is not accounted for in an assessment. It was suggested that enabling responsible risk taking is an area for quality improvement.

* + 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 |
| Timely and stepped assessment | NICE CGXX (in development) Recommendation 1.5.1 |
| Ensure comprehensive health assessments for children and young people who present with challenging behaviour | NICE CGXX (in development) Recommendation 1.2.1 and 1.5.5 |
| Assessment of environmental impact on behaviour | NICE CGXX (in development) Recommendation 1.5.2 and 1.5.5 |
| Inclusion of responsible risk taking in behaviour risk assessments | No recommendations in the source guidance. |

### Timely and stepped assessment

NICE CGXX (in development) – Recommendation 1.5.1

1.5.1 When assessing behaviour that challenges in people with a learning disability, follow a graduated approach (see recommendations 1.5.4–1.5.12). Aim to gain a functional understanding of why the behaviour occurs and develop a behaviour support plan (see recommendation 1.5.13) as soon as possible.

### Ensure comprehensive health assessments for children and young people who present with challenging behaviour

NICE CGXX (in development) – Recommendation 1.2.1

1.2.1 Offer an annual physical health check to people with a learning disability in all settings. Carry out the physical health check together with a family member, carer or healthcare professional or social care practitioner who knows the person. Ensure that it takes into account any known or emerging behaviour that challenges and how it may be linked to any physical health problems, and contains:

* a physical health review
* a review of all current health interventions, including medication and any side effects
* an agreed and shared care plan for managing any physical health problems.

NICE CGXX (in development) – Recommendation 1.5.5

As part of initial assessment of behaviour that challenges, take into account:

* developmental history
* any previous interventions for behaviour that challenges
* social and interpersonal history, including relationships with family members, carers or staff, including teachers
* the person's abilities and needs (in particular, their expressive and receptive communication)
* recent life events
* any physical or mental health problems, and the effect of prescribed and other medication
* the person’s sensory sensitivities, preferences and needs
* the physical environment, including heat, light, noise and smell
* the care environment, including the range of activities available, how it engages people and promotes choice, and how well organised it is.

### Assessment of environmental impact on behaviour

NICE CGXX (in development) – Recommendation 1.5.2

When assessing behaviour that challenges ensure that:

* the person and their family members or carers are engaged in the assessment process
* the complexity and duration of the assessment is proportionate to the severity, impact, frequency and duration of the behaviour
* everyone involved in delivering an assessment understands the criteria for moving to more complex and intensive assessment
* the person being assessed remains at the centre of concern and is supported throughout the process
* all individual and environmental factors that may lead to behaviour that challenges are taken into account
* assessment is a flexible rather than fixed process, because factors that trigger and maintain behaviour may change over time
* assessments are repeated after any change in behaviour
* assessment is outcome focused
* the resilience and resources of family members and carers are assessed
* the capacity, sustainability and commitment of the staff delivering the behaviour support plan (see recommendation 1.5.13) are assessed.

NICE CGXX (in development) – Recommendation 1.5.5

As part of initial assessment of behaviour that challenges, take into account:

* developmental history
* any previous interventions for behaviour that challenges
* social and interpersonal history, including relationships with family members, carers or staff, including teachers
* the person's abilities and needs (in particular, their expressive and receptive communication)
* recent life events
* any physical or mental health problems, and the effect of prescribed and other medication
* the person’s sensory sensitivities, preferences and needs
* the physical environment, including heat, light, noise and smell
* the care environment, including the range of activities available, how it engages people and promotes choice, and how well organised it is.
  + 1. Current UK practice

Published studies on current practice were only identified for the area of comprehensive health assessments. Areas without current data are based on stakeholder’s knowledge and experience from local audit data.

One study of out-of-area provision for adults with intellectual disabilities and challenging behaviour looked at a number of areas within assessment (Barron, et al. 2011)[[8]](#footnote-8). 54 service providers from five London boroughs were surveyed, including services from the voluntary sector, the private sector, NHS hospitals, social services housing and independent hospitals. It should be noted that services ‘self-reported’ against survey questions. Therefore, the data should be treated with caution. The majority of providers (87.4%, n=47) stated that they had a comprehensive assessment process and used support plans detailing positive behavioural interventions (88.8%, n=48). However, only 18% of all the services surveyed reported that they had support plans in place for all service users with challenging behaviour. As stated previously, these findings were based on self-report and a more general question in the 2012 CQC Review of Learning Disability Services in 150 Trusts found that comprehensive assessments had not been conducted in all cases, or lacked detail for care planning[[9]](#footnote-9). The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) conducted over 2010–2012 found that 71% had received an Annual Health Check in the year before death, but 12% had never had an Annual Health Check[[10]](#footnote-10). The inquiry also noted that the quality and recording of Annual Health Checks was very varied and meant that in some instances it was difficult to conclude that a full health assessment had been conducted.

* 1. Interventions
     1. Summary of suggestions

### Provide opportunities to engage in meaningful occupation or valued activity

Stakeholders commented that the relationship between activity, occupation and challenging behaviour is currently under recognised and undervalued. Moreover, responses suggested that people with learning disabilities and challenging behaviour are deprived of the opportunity to engage in meaningful occupation/activity, or they are forced to take part in activities that are meaningless to them.

### Use of person-centred positive behaviour support plans

Positive behaviour support was described by stakeholders as the preferred approach when working with people with learning disabilities who exhibit behaviours described as challenging. It was suggested that the use of mutually agreed person-centred positive behaviour support plans would improve transitions and ensure continuity for people. Stakeholders stated that although significant improvement in outcomes has been demonstrated with positive behaviour support, making this an area for quality improvement would drive practice into the mainstream. It was also highlighted that positive behaviour support also generates a set of measurable standards that can be used for quality assurance processes.

### Clear documented risk assessment of reactive strategies with details of monitoring and review

The issue of overreliance on reactive strategies, such as restraint, was raised by stakeholders who commented that this could prevent service users having opportunities to learn adaptive skills. Comments suggested that reactive strategies should be clearly risk assessed in care plans and the method of monitoring and review documented to ensure a reduction in use of strategies and use of the least restrictive strategies. Respondents indicated that although schools have training about restraints within particular frameworks (e.g. Team Teach), the protocols may not always clearly state the rationale for the strategy or who it was agreed with and how it will be monitored.

* + 1. Selected recommendations from development source

Table 7 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 7 to help inform the Committee’s discussion.

Table 7 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Provide opportunities to engage in meaningful occupation or valued activity. | NICE CGXX (in development) Recommendation 1.5.13 |
| Use of person-centred positive behaviour support plans | No recommendations in the source guidance. |
| Clear documented risk assessment of reactive strategies with details of monitoring and review | NICE CGXX (in development) Recommendation 1.8.2 and 1.8.3 |

### Provide opportunities to engage in meaningful occupation or valued activity.

NICE CGXX (in development) – Recommendation 1.5.13

1.5.13 If the behaviour that challenges continues after assessment, develop a behaviour support plan based on a shared understanding about the function of the behaviour and what maintains it. This should:

* identify proactive strategies designed to stop the conditions likely to promote behaviour that challenges, including changing the environment (for example, reducing noise, increasing predictability) and promoting active engagement through structured and personalised daily activities, including the school curriculum for children and young people
* identify adaptations to a person’s environment and routine, and strategies to help them develop an alternative behaviour to achieve the function of the behaviour that challenges by developing a new skill (for example, improved communication, emotional regulation or social interaction)
* identify secondary prevention strategies to calm the person when they begin to show early signs of distress, including:
* individual relaxation techniques
* distraction and diversion onto activities they find enjoyable and rewarding
* identify reactive strategies to manage any behaviours that are not preventable (see section 1.8), including how family members, carers or staff should respond if a person’s agitation escalates and there is a significant risk of harm to them or others
* incorporate risk management and take into account the effect of the behaviour support plan on the level of risk
* be compatible with the abilities and resources of the person’s family members, carers or staff, including managing risk, and can be implemented within these resources
* be monitored using data collection and reviewed regularly
* identify any training for family members, carers or staff to improve their understanding of behaviour that challenges in people with a learning disability.

### Clear documented risk assessment of reactive strategies with details of monitoring and review

NICE CGXX (in development) – Recommendation 1.8.2

1.8.2 Plan reactive strategies from an ethically sound basis and use a graded approach that considers the least aversive and restrictive alternatives first. Encourage the person and their family members or carers to be involved in planning and reviewing reactive strategies whenever possible.

NICE CGXX (in development) – Recommendation 1.8.3

1.8.3 If a restrictive intervention is used as part of a reactive strategy, carry out a thorough risk assessment. Take into account:

* any physical health problems and physiological contraindications to the use of restrictive interventions, in particular manual and mechanical restraint
* any psychological risks associated with the intervention
* any known biomechanical risks, such as cardiovascular and musculoskeletal risks
* any sensory sensitivities, such as a high or low threshold for pain or touch.
  + 1. Current UK practice

Current practice data was not identified for all areas within the theme of interventions suggested by stakeholders. However, practice data was identified for the following areas:

* opportunities to engage in activities
* monitoring and review of reactive strategies.

The Review of Learning Disability services published in 2012 by the Care Quality Commission (CQC), which looked at 150 Trusts, included a standard on access to and adequate support for engagement in meaningful activities[[11]](#footnote-11). The review found that some sites were compliant with this standard and provided a range of meaningful activities, but there was variation across sites and other Trusts were reported as only offering a limited range of activities or not meeting the needs of individuals. Limited access to activities was exacerbated by insufficient staffing, with activities cancelled due to staff shortages. Moreover, a lack of personalised care planning meant that the needs of individuals were not always met. The review concluded that person-centred planning was not embedded into care for all people using services. Although care planning appeared to be routinely undertaken, the review found a lack of information about individual preferences and also care plans that lacked basic detailed information on physical and mental health needs.

For the use of reactive strategies, no current data was identified that gave an overview of the use of a range of reactive strategies. However, the 2014 Learning Disability Census included information on the use of rapid tranquilisation. The survey asked if patients had received rapid tranquilisation in the 28 days prior to the 30th September 2014. It was found that 12% (375) of adult patients had received this. In addition, of the 820 patients who had experienced at least one adverse incident and at least one restrictive measure, 26% (215) had received rapid tranquilisation. For those in the under 18 age group, the figures receiving rapid tranquilisation had increased. Whilst in 2013 79% of under 18s (125) had not received any rapid tranquilisation in the 28 days prior to the survey, in 2014 those receiving rapid tranquilisation was 88%[[12]](#footnote-12).

The CQC review of Learning Disability services[[13]](#footnote-13) also looked at the use of restraint. This concluded that the use of restraint was not monitored appropriately or well understood by service providers. The use of physical restraint in hospital settings was also reviewed by Mind in 2013, which used Freedom of Information requests to 54 mental health trusts in England[[14]](#footnote-14). Most of the Trusts responded, with only 3 Trusts not replying. The report stated that there was a wide variation in the use of physical restraint in England, with one Trust reporting 38 incidents in one year and another Trust reporting over 3,000 incidents. Trusts reported using physical restraint for medication purposes in over 4,000 recorded incidents. One Trust reported 923 incidents of face down physical restraint in one year. It was noted that some staff did not appear to find out why a person refused medication before using physical restraint to administer it. The report also highlighted that some Trusts have ended the use of face down physical restraint, using respect-based principles to develop other forms of restraint. It should be noted that this data covered all patients in inpatient mental health units, not Learning Disability patients only.

* 1. Medication
     1. Summary of suggestions

**Ensure a clear rationale for prescribing and shared decision making**

Stakeholders commented that it was vital for the use of medication for challenging behaviour with children, young people and adults with a learning disability to be accompanied by a clear rationale. Responses indicated that this was not always the case in practice. Retrospective reviews of case notes suggest that where rationale is recorded the intended outcome is not always detailed enough to enable assessment of the benefits and risks of continuing treatment.

Stakeholders also commented that shared prescribing decisions between the individual and the prescriber should be supported. In order for shared decisions to be made, stakeholders highlighted that accessible information on medication was needed. It was stated that this should be information in an appropriate form about the prescribed medication, indication, expected benefits and possible side effects and should be given to the individual and to their family members or carers.

It was suggested that although prescribing information may be included in medical notes, it is recorded in a variety of different places, which can mean it is difficult to locate and subsequently overlooked. This can lead to medication being prescribed without review for long periods. Stakeholders stated that a separate care plan would focus on medication and include the rationale, target symptoms, frequency of review and any monitoring required with details of who the review should be completed by and how undertaken.

### Appropriate monitoring and review of medication

Stakeholders highlighted that where antipsychotic medication is prescribed to manage behaviours that challenge, it is vital that the benefits of prescribing outweigh the risks. Risk of harm, including associated side effects, such as weight gain and metabolic syndrome, can increase if antipsychotic medication is initiated, but not appropriately reviewed or monitored. Responses suggested that this is a key area for quality improvement. It was stated that systematic review of medication could reduce potential excess morbidity due to side effects, in particular those associated with antipsychotics. Stakeholders highlighted that the use of psychotropic, hypnotics and anxiolytics can precipitate aggression and agitation and these should not be used for more than four weeks. However, discontinuation can be difficult to achieve and it was suggested that psychotropic medications are being prescribed excessively for challenging behaviours, particularly in the absence of a diagnosis of mental disorder. One stakeholder indicated that there should be six monthly reviews of prescribed medications for this group of people.

Moreover, it was suggested that people with a learning disability may not have the same access to specialist and community pharmacists for advice or completion of medicine use reviews. Stakeholders recommended that access to medication use reviews conducted by a pharmacist would provide an additional check to ensure that medication was being used and monitored appropriately. This would also help to ensure that individuals and their carers understand why the specific medication has been prescribed. This area was noted by stakeholders as an area for further research and development.

* + 1. Selected recommendations from development source

Table 8 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 8 to help inform the Committee’s discussion.

Table 8 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Ensure a clear rationale for prescribing and shared decision making | NICE CGXX (in development) Recommendation 1.7.2 and 1.7.4 |
| Appropriate monitoring and review of medication | NICE CGXX (in development) Recommendation 1.7.3 and 1.7.5 |

### Ensure a clear rationale for prescribing and shared decision making

NICE CGXX (in development) – Recommendation 1.7.2

1.7.2 When prescribing medication for behaviour that challenges, take into account side effects and develop a care plan that includes:

* a rationale for medication, explained to family members and carers
* how long the medication should be taken for
* a strategy for reviewing the prescription and stopping the medication.

NICE CGXX (in development) – Recommendation 1.7.4

1.7.4 When choosing which antipsychotic medication to offer, take into account side effects, acquisition costs, the person’s preference (or that of their family member or carer, if appropriate) and response to previous antipsychotic medication.

### Appropriate monitoring and review of medication

NICE CGXX (in development) – Recommendation 1.7.3

1.7.3 Consider antipsychotic medication for behaviour that challenges if psychological or other interventions are insufficient or cannot be delivered alone because of the severity of risk to self or others. Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist, or a neurodevelopmental paediatrician with expertise in learning disabilities) who should:

* identify the target behaviour
* decide on a measure to monitor effectiveness (for example, direct observations, the Aberrant Behaviour Checklist or the Adaptive Behaviour Scale), including frequency and severity of the behaviour and impact on functioning
* start with a low dose and use the minimum effective dose needed
* only prescribe a single drug
* review the effectiveness and any side effects of the medication after 3–4 weeks
* stop the medication if there is no indication of a response at 6 weeks
* not prescribe p.r.n. (as-needed) medication for more than 4 weeks
* review the medication if the person’s environmental or personal circumstances change.

NICE CGXX (in development) – Recommendation 1.7.5

1.7.5 If there is a positive response to antipsychotic medication:

* conduct a full multidisciplinary review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping)
* only continue to offer medication that has proven benefit.
  + 1. Current UK practice

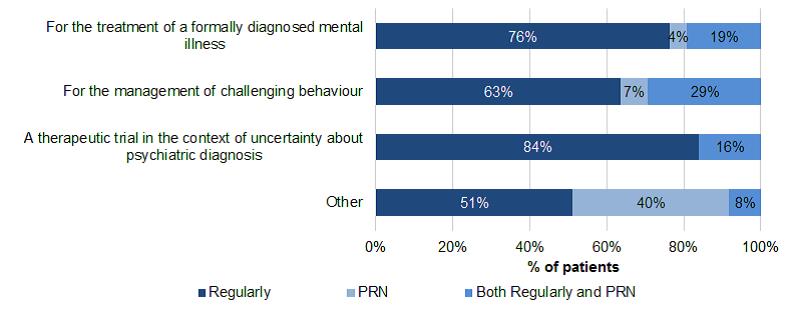
The Learning Disability Census, conducted as a snapshot survey on the 30th September 2014, found that the overall use of antipsychotic medication for adults had increased since 2013[[15]](#footnote-15). The Census data reported an increase from 68% (2,220) of adult patients receiving antipsychotics, either regularly or as needed, commonly termed PRN or pro re nata (PRN), to 73% (2,345).

Table 9: Number and percentage of adult patients by use of antipsychotic medication in the 28 days prior to census day 2013 & 2014

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Number** | | **Percent** | |
|  | 2013 | 2014 | 2013 | 2014 |
| **All patients** | 3,250 | 3,230 | 100% | 100% |
| **None** | 1,030 | 885 | 32% | 27% |
| **Yes** | 2,220 | 2,345 | 68% | 73% |
| of which: Regularly | 1,316 | 1,680 | 40% | 52% |
| PRN | 156 | 150 | 5% | 5% |
| Both Regularly and  PRN | 748 | 515 | 23% | 16% |

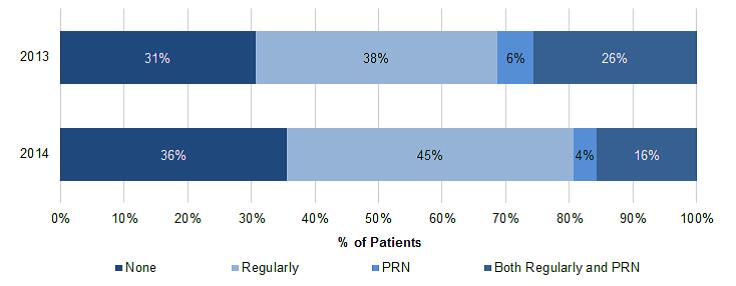
An increase in prescribing was found in both male and female adult patients. The 2014 census also included a new question that asked why antipsychotic medication had been administered to adults. Figure 1 below shows that 64% of patients (1,510) received medication for treating a formally diagnosed mental illness, 31% (715) received it for the management of challenging behaviour, 1% (30) patients received it for a therapeutic trial and 4% (85) were labelled as ‘Other’ reason. The figure below also shows whether this was regular use, PRN or both and indicates that ‘regular’ was the predominant method of administration for the management of challenging behaviour (63%).

Figure 1: *Reasons for the use of antipsychotic medication 28 days prior to census day by method of administration 2014*



Practice data around medication for the under 18s was also included in the Census questions. It should be noted that the data only covers those in inpatient units at the time of the survey in September 2014. These figures differed from the adult numbers in suggesting a decrease in the use of antipsychotic medication between 2013 and 2014. In 2013 31% (49) of under 18 patients (n=16) did not have any antipsychotics, whereas the figure in 2014 was 36% (55; n=160).

Figure 2: *Use of antipsychotic medication for patients under 18 years of age 28 days prior to census day 2013 & 2014*

**

Prescribing practice in NHS Trusts was also reported in a study conducted by the Prescribing Observatory for Mental Health (POMH-UK), published in 2011[[16]](#footnote-16). The data was gathered from 39 specialist mental health Trusts across England, Wales, Scotland and Northern Ireland and included 145 clinical teams and data for 2319 patients, 79% of whom were outpatients. They audited practice against standards taken from 2006 guidance on using medication to manage behaviour problems in adults with a learning disability[[17]](#footnote-17) and from the 2009 NICE guideline for the management of schizophrenia[[18]](#footnote-18).

The audit looked at the documentation of prescribing and found that the indication for treatment with antipsychotics was documented in 95% (2194) of the sample. For annual review of medication, a review was conducted in 96% (1913) of those prescribed an antipsychotic for at least a year. A change in dosage occurred following review in over a quarter of cases. The rationale underpinning a decision at the review was documented in 92% (1728) of cases. The recording of side effects of medication was less routine, being documented in only 69% (1378) of those prescribed antipsychotic medication for a year more. For specific side effects documentation was poor. In 12% of cases there was no documentation of specific side effects and almost half of cases had no assessment of body weight (44%, 883), or lipid profile (43%, 848). Although the rationale for prescribing was documented in the majority of cases, the most common indication was comorbid psychotic disorder. However, almost 60% of the sample did not have a formal diagnosis of psychotic illness. Anxiety, agitation and aggressive behaviour were also cited as indications for prescribing. Half of the cases included more than one clinical reason for prescribing and a quarter had three or more indications. The authors also noted that the use of antipsychotics to manage behavioural problems was ‘common’ in the sample and this was particularly evident in a sub-sample without a diagnosed psychiatric disorder in addition to their intellectual disability. They highlighted that this sub-sample included a high representation of people with severe or profound intellectual disability compared to the wider sample. Overall, the authors concluded that the majority of prescribing was consistent with the evidence base and whilst the efficacy of treatment was actively monitored, assessment of side effects was an area for improvement. The authors also noted that although the data may not be generalizable to people being cared for in other settings, the data was gathered from 39 Trusts across the UK, so is potentially representative of practice.

* 1. Family and carer support
     1. Summary of suggestions

### Improved training and support in communication skills for people with learning and disabilities and their families and carers

Stakeholder comments stated that the link between communication and challenging behaviour is well established. It was suggested that provision of effective communication methods for children and adults and their families and carers is likely to reduce behavioural challenges and help to develop a capable communication environment.

### Training and support for families

The need for improvement around support for families and carers also included a wider suggestion that an increase in training and support generally would improve the quality of people’s experiences.

One stakeholder stated that research suggests paid carers may require further skills in order to manage challenging behaviour effectively. However, family carers may have a different set of needs which should be met in order to enable them to care for a person with challenging behaviour. Responses highlighted the need to prioritise support for families in particular to reduce carer stress and burn-out.

* + 1. Selected recommendations from development source

Table 9 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 9 to help inform the Committee’s discussion.

Table 9 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Improved training and support in communication skills for people with learning and disabilities and their families and carers | NICE CGXX (in development) Recommendation 1.6.2 and 1.6.4 |
| Training and support for families | NICE CGXX (in development) Recommendation 1.3.3 |

### Improved training and support in communication skills for people with learning and disabilities and their families and carers

NICE CGXX (in development) – Recommendation 1.6.2

1.6.2 Parent-training programmes should:

* be delivered in groups of 10 to 15 parents or carers
* be accessible (for example, take place outside normal working hours or in the parent or carer's home or other community-based settings with childcare facilities)
* focus on developing communication and social functioning
* typically consist of 8 to 12 sessions lasting 90 minutes
* follow a developer's manual
* employ materials to ensure consistent implementation of the programme.

NICE CGXX (in development) – Recommendation 1.6.4

1.6.4 Preschool classroom-based interventions should have multiple components, including:

* curriculum design and development
* social and communication skills training for the children
* skills training in behavioural strategies for parents or carers
* training on how to mediate the intervention for teachers.

### Training and support for families

NICE CGXX (in development) – Recommendation 1.3.3

1.3.3 When providing support to family members or carers:

* recognise the impact of caring for a person with a learning disability and behaviour that challenges
* explain how to access family advocacy
* consider family support and information groups if there is a risk of behaviour that challenges, or it is emerging
* consider formal support through disability-specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges.
  + 1. Current practice

The Council for Disabled Children have recently published a report on communication skills for children and young people concluding that many do not receive adequate support to develop communication skills (2015)[[19]](#footnote-19). They cite an Ofsted report published in 2012, which highlights a gap in adequate training for school teachers in communication skills. There was no current practice data identified for adults.

* 1. Supporting infrastructure

**Multi-disciplinary team composition**

Stakeholders commented that investment in local multi-disciplinary teams could provide positive behaviour support approaches and thereby prevent future high cost out of area placements, including residential schools for children, and “specialist” provision for adults. The missed targets of the post-Winterbourne concordat were cited as evidence that the capacity and capability of local services needs to improve.

**Use of a named keyworker approach**

Responses highlighted anecdotal evidence suggesting that parents and carers have to repeatedly give information to different workers involved in care. A named keyworker system was described as enabling co-ordination of a person’s care in mutually agreed support plans and also addressing the need for continuity and minimal transitions.

* + 1. Selected recommendations from development source

Table 9 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 9 to help inform the Committee’s discussion.

Table 9 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Multi-disciplinary team composition | NICE CGXX (in development) Recommendation 1.1.5 |
| Use of a named keyworker approach | No recommendations in the source guidance. *It should be noted that the Guideline Development Group are currently considering a further recommendation to address this area.* |

### Multi-disciplinary team composition

NICE CGXX (in development) – Recommendation 1.1.5

1.1.5 If initial assessment (see section 1.5) and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing routine assessment and interventions have access to:

* specialist assessment
* specialist support and intervention services
* advice, supervision and training to support the implementation of any care or intervention.

Specialist support and intervention services should include nurses, psychologists, psychiatrists, social workers, and speech and language therapists. Occupational therapists, physiotherapists, physicians, paediatricians and pharmacists may also be involved.

* + 1. Current UK practice

The Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD)[[20]](#footnote-20) reviewed multi-disciplinary input and found that most providers surveyed had planned access to a community or in-house multi-disciplinary team. The majority of providers met over 50% of the criteria for this, particularly for psychologists, psychiatrists and nurses. The two independent hospitals in the survey reported no access to speech and language therapists or occupational therapists.

Looking more widely at staffing in care services for people with learning disabilities and challenging behaviour, the National Audit Office report, published in February 2015, identified reduced staff, recruitment freezes and restructures in community based learning disability teams due to budget pressures[[21]](#footnote-21). It stated that the reduction in specialist learning disabilities teams had contributed to delays in people receiving appropriate care packages and increased the risk of hospitalisation and readmissions.

* 1. CAMHS services
     1. Summary of suggestions

### Early and timely access to CAMHS services

The area of access to CAMHS services was raised by stakeholders as an area for quality improvement. The issues with access were described as arising from confusion around the criteria for referral being too narrowly defined and gaps in CAMHS service provision. Stakeholders cited evidence given to a Health Select Committee in 2014 showing that limited access to CAMHS services resulted in people with learning disabilities and challenging behaviour seeking help from paediatric services It was stated that aside from undertaking health assessments to identify any health issues that may contribute to, or cause, challenging behaviour, paediatric services should not be managing this group of people.

* + 1. Selected recommendations from development source

Table 10 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 10 to help inform the Committee’s discussion.

Table 10 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Early and timely access to CAMHS services. | No recommendations in the source guidance. |

* + 1. Current UK practice

The Paediatric Mental Health Association conducted two surveys exploring the impact of changes to CAMHS provision, to gather data for a 2014 Health Select Committee submission[[22]](#footnote-22). One survey was sent to community paediatricians by email and had 167 responses. Results indicated that referrals to community paediatric departments primarily for emotional and behavioural problems have increased over the last three years, with 56% of respondents reporting 40% or more of their work as emotional and behavioural in 2014. The survey pointed to the criteria around a diagnosis for access to CAMHS as a barrier, reporting that 83.2% of respondents identified an increase in thresholds for access over the last three years. A second survey amongst paediatric and liaison psychiatric units in the UK underlined the suggestions around reduced access to CAMHS services. Almost half (43%) of respondents identified reduced support for young people as a factor in the increases in self-harm admissions and poor quality of service or a decrease in CAMHS provision was cited in 70% of responses.

* 1. Additional suggestions not meeting technical criteria for statement development:

### Training and support for staff

It was commented that standards developed from the guideline would highlight a gap in skills within the services for people with learning disabilities whose behaviour can be challenging. Therefore, training for staff should be viewed as an area for quality improvement. Stakeholders also highlighted three specific areas of staff training for further improvement:

* the use of a variety of communication methods by all staff who support children and adults with learning disabilities
* training for school staff in positive behaviour support approaches
* the need for people to have access to teams with expertise, knowledge and skills in functional analysis and intervention.

It was commented that teams have inconsistent disciplinary compositions and levels of training, which leads to variation in quality of assessment.

The quality standard should not contain any statements on training and competencies. Staff being trained and competent is an underpinning concept of all quality standards. An additional paragraph has been added to the overview for each quality standard which can make reference to specific examples of training and competency frameworks where the QSAC feel this is important.

**Use of the Health Equalities Framework developed by the Learning Disability Consultant Nurses Group**

Stakeholders commented that there was a need to develop an outcome measure around the theme of tackling health inequalities following the Winterbourne review. It was suggested that the work of the Learning Disability Consultant Nurses Group in developing the Health Equalities Framework (HEF) provides an approach for specialist learning disability services to agree and measure outcomes. This could also be used by services, carers and families in partnership to agree personalised outcomes.

NICE quality standards focus on areas of practice that are in need of aspirational but achievable improvements. Quality standards identify related overarching outcomes and the national outcome frameworks that the quality standard could contribute to achieving. They also contain outcome measures specific to each quality statement. Quality standards do not suggest the implementation of developed outcomes frameworks.

# Appendix 1: Suggestions from stakeholder engagement exercise

| **ID** | **Stakeholder** | **Key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- | --- |
| 1 | SCM 1 | Early intervention support for children with learning disabilities who are beginning to display behaviours described as challenging. This should include support and training for families, and all those who have a role in supporting the child. | Early intervention and prevention approaches are widely accepted. Children with learning disabilities are at greater risk of developing behaviour described as challenging. | There is currently no systematic strategic approach to ensuring that children and their families get the right support early. | Early Intervention for children with learning disabilities whose behaviours challenge. The Challenging Behaviour Foundation 2014 |
| 2 | SCM 1 | Additional developmental areas of emergent practice  Early holistic support for families of children with learning disabilities BEFORE the child has started to develop behaviour described as challenging. | This is the prevention approach – targeting support before behaviours develop, adopting a preventative approach | There has been little/ no work in this area | Work by Dr Nick Gore at Tizard Centre, and Prof Chris Oliver |
| 3 | Royal College of Nursing | Early Intervention/Prevention (e.g. Parent/carers should have access to skills training in behavioural strategies) | There is evidence that early intervention has a role to play in preventing onset of challenging behaviour.  Without early intervention, there is a risk of challenging behaviours developing and becoming well established within a maintenance cycle, impacting on efficacy of later treatment. As such, parents/carers should have access to support/parent training/skills development in behaviour strategies post diagnosis and/or in early years. | Level of support for parents/carers post learning disability diagnosis and parents/carers of young children with severe intellectual disabilities, with specific syndromes (e.g. Smith-Magenis, Cornelia de Lange), and severely compromised communication is patchy.  Anecdotally, parents may have attended psychoeducational parenting programmes primarily based on mainstream children (e.g. Triple P) but not groups that focus on understanding behaviour principles, development of communication and prevention of challenging behaviour. | Plant, K. M., & Sanders, M. R. (2007). Reducing problem behaviour during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities, 28*, 362-385. |
| 4 | SCM 2 | Improving timely assessment and prompt treatment for managing challenging behaviour | Assessments of incidents of challenging behaviour should follow a stepped pathway and move promptly through to the next step at predetermined intervals. Currently assessments can take as long as three months to be completed with management plans for psychosocial interventions not implemented for several more months often dependent on provider availability to support such plans. | Delays in assessments and implementation of treatment beyond pharmacological interventions can increase paid and family carer burden and prove detrimental to the patient’s quality of life  Drawing up challenging behaviour pathways with clear progression criteria through the steps should be required from each community ID service.  An audit of community ID services suggests that several do not have integrated arrangements or stepped care for assessing and treating challenging behaviour. Often patients are referred to other services within the same area (generic ID team receiving a first referral which is then referred on to a more specialist team) and this may result in duplication and also increase in waiting lists of more than six months. In the meantime, if risk is deemed medium or high medication may be used which may end up being given indefinitely. | For example, the autism and ADHD guidelines could provide an example for setting up such pathways and descriptions of the patient journey. |
| 4 | The Royal College of Paediatrics and Child Health | Key area for quality improvement 2 | To ensure a comprehensive health assessment is undertaken in children and young people with a learning disability who present with challenging behaviour since underlying health problems (esp. painful ones), may exacerbate or even cause challenging behaviour, yet pass unnoticed and untreated. This may require adaptations to the normal examination technique and/or investigation procedures.  Accountability across services and Agencies | Underlying health problems, especially painful ones, may exacerbate or cause challenging behaviour and require treatment to facilitate resolution (or at least improvement), of the associated behaviour. | Mencap’s Death By Indifference report describing severe consequences of lack of access to, or incorrect health care offered to, people with a learning disability:  <https://www.mencap.org.uk/death-by-indifference>  South West of England survey showing unmet dental needs, and the importance of using adapted equipment, in children and young people with learning difficulties:  <http://www.pencru.org/evidence/dentistry/> |
| 5 | SCM 3 | The impact of a person’s environment on behaviour that challenges | The environment includes the physical environment, the social environment, the sensory aspects of that environment, the human aspects (i.e. the people within the environment and their knowledge, beliefs and training), and the opportunities the environment offers a person.  NICE highlight the importance of individual capable environments as impacting on behaviour that challenges. | The environment that the person lives in forms the basis for supportive interventions.  Careful consideration need to be given to how the environment is set up to support the person, considering their individual needs and preferences.  This can be difficult when people are sharing accommodation, which is common, which can impact on the consistency of environmental support. | Challenging behaviour:  a unified approach.  Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving  abusive or restrictive practices  <http://www.bps.org.uk/sites/default/files/documents/challenging_behaviour_-_a_unified_approach.pdf> |
| 6 | Enfield Learning Disability Partnership Board Services | Behaviour Risk Assessments | Supporting people whose behaviour can be challenging presents significant issues for risk management, in terms of the safety of the person being supported, those around them, and the risk of lost life opportunities. | Life opportunities for people whose behaviour can be challenging can often be limited by risk management strategies that do not take into account responsible risk taking. Clear guidance in this matter could have a significant positive effect on people’s lives. | BILD – [Risk in challenging Behaviour: a good practice guide for professionals](http://www.bild.org.uk/our-services/books/positive-behaviour-support/risk-in-challenging-behaviour/) |
| 7 | College of Occupational Therapists | Impact of activity and occupational on the reduction of challenging behaviour | The link/relationship between activity, occupation and challenging behaviour is significantly under recognised and undervalued. | People with learning disabilities and challenging behaviour are routinely deprived of the opportunity to engage in meaningful occupation/activity, or they are forced to take part in activities that are meaningless to them.  The College supports the principal that everyone has the human right to engage in meaningful occupation. Although, all services and teams should have the capacity to address this, inclusion in a quality standard will help prioritise and implement this. | The World Federation of Occupational Therapists has produced a Position Statement on Human Rights in relation to human occupation and participation. This asserts that the opportunity to engage in personally satisfying occupations is a fundamental human right.  <http://www.wfot.org/ResourceCentre.aspx> |
| 8 | SCM 3 | The impact of engaging in meaningful occupation on behaviour that challenges | Engaging in valued activity (occupation) is part of various approaches noted as useful by NICE in addressing behaviour that challenges, e.g. PBS, active support.  It is also highlighted in various research and guidance around provision of services for people who display behaviour that challenges, e.g. Mansell, 2007. | Engaging in meaningful occupations is a basic human right, however, many people with learning disabilities and behaviour that challenges do not have regular opportunities to engage in valued activities and occupations. | The world federation of occupational therapists position statement on human rights states that:   * People have the right to participate in a range of occupations that enable them to flourish, fulfil their potential and experience satisfaction in a way consistent with their culture and beliefs * People have the right to participate in occupation, and through engaging in occupation, to be included and valued as members of their family, community and society   <http://www.wfot.org/ResourceCentre.aspx> |
| 10 | Enfield Learning Disability Partnership Board Services | Positive Behaviour Support | Positive behaviour support approaches have become established as the preferred approach when working with people with learning disabilities who exhibit behaviours described as challenging. | Significant improvements in outcomes have been demonstrated through the use of PBS, and adoption as recognised best practice will further drive into the mainstream of care and support for people whose behaviour can be challenging.  Positive behaviour support also gives rise to a set of measurable standards that can be used for quality assurance purposes. | Department of Health (2014) Positive and Proactive Care: reducing the need for restrictive interventions;  British Psychological Society (2004) Psychological interventions for severely challenging behaviours shown by people with learning disabilities: clinical practice guidelines, and  [The Challenging Behaviour Charter](http://www.challengingbehaviour.org.uk/learning-disability-files/CBF-Charter-2013.pdf) |
| 11 | SCM 1 | Improve communication training and support for children and adults with LD and for all those who support them | Children and adults with learning disabilities who display behaviour described as challenging commonly have difficulties communicating.  The link between communication and challenging behaviour is well established.  Children and adults with LD are  likely to be supported in various  settings by staff who are unable to  use a variety of communication  methods | Providing children and adults with effective communication methods is likely to reduce behavioural challenges.  Skill development is an important factor.  Supporting and training families and support staff in communication can help to develop a capable communication environment | LD census  CQC Learning Disability Review  RCSLT good communication standards |
| 12 | Royal College of Nursing | Reactive Strategies  (e.g. use of restraints) | An overreliance on reactive strategies is likely to prevent service users having opportunities to learn adaptive skills. Reactive strategies should be clearly risk assessed in care plans, with the method of monitoring and review being clear to ensure reduction/least restrictive strategies over time. | Many schools have training about restraints within particular frameworks (e.g. Team Teach) – however, protocols may not always clearly state the rationale for strategy and who it was agreed with, and how it will be monitored. |  |
| 11 | College of Mental Health Pharmacy | **“**Appropriate prescribing and monitoring of pharmacological interventions for behaviours that challenge” | When children, young people and adults with a learning disability are prescribed an antipsychotic (or other medication, e.g. benzodiazepine) to manage behaviours that challenge- it is vital that there is a clear rationale for treatment, and that medication is appropriately monitored and reviewed. Where ever possible shared decision making between the individual and prescriber should be supported (may require medicine information to be available in easy-read format)- *“no decision about me without me”*  It is also important that adequate information, in an appropriate form(s), is provided to the individual and/ or their family/ carers about the prescribed medication, indication, expected benefits and possible side effects.  Where indication for treatment is unclear or side effects observed/ experienced- this may result in the medication not being taken/ administered as intended and therefore benefits of treatment not realised.  Also- medication prescribed for behaviours that challenge may be used outside the manufacturer’s licensed indication- therefore it is important that prescribers inform the individual and/ or family/ carers about this and what this actually means in practice- however it also reinforces the importance of ensuring that where prescribed- there is a clear rationale for use and that treatment is reviewed frequently and monitored appropriately. | Retrospective reviews of clinical notes locally demonstrate that the reason and rationale for initiating medication to manage challenging behaviour (CB) is not always clear- or even recorded, and where it is stated that a medication(s) is for CB- the intended outcome/ measure to monitor effectiveness is not always clear, with subsequent entries such as “behaviour has improved” not being detailed enough to robustly review the benefits and risks of continuing treatment.  There should be a separate care plan to focus on medication prescribed for CB- to include rationale, target symptoms, frequency of review and any monitoring required (and who will complete the review/ how & where the monitoring will be undertaken). Whist this information may be included in medical notes- it is sometimes recorded in a variety of different places-which means it is difficult to locate- may be missed/ overlooked- and is not easily communicated to other prescribers/ providers of care. This can result in medication being prescribed for long periods of time without review and/ or recommended monitoring.  It has already been reported that people with a LD have a shorter life expectancy and increased risk of early death when compared with the general population. Therefore- if antipsychotic medication is prescribed to manage behaviours that challenge- it is vital that the benefits of any prescribed medication outweigh the risks. If antipsychotic medication is initiated and then not appropriately reviewed or monitored, then it is likely that the risk of harm will increase- and associated side effects (especially if unmonitored/ unchecked) including weight gain and metabolic syndrome will add to increasing the risk of all-cause mortality rates ( which is already reported to be 3 times higher than the general population).  Antipsychotic medication may also add to know risk factors for people with a learning disability (i.e. increased risk of choking)- and therefore prescribers also need to me mindful of the mechanism of action and potential side effects associated with pharmacological interventions.  It is already acknowledged that good practice includes appropriate monitoring of medication (such as anti-psychotic and antiepileptic medicines), but in practice- despite NICE guidance (CG schizophrenia) and specialist recommendations to GP to continue monitoring (which should be included in the annual health checks), there is still a need for considerable improvement.  For example an audit cycle completed by Dr Shankar has demonstrated that initially (2010) 83% GPs followed 85% recommendations (for monitoring), but that a recent re-audit has shown adherence has now fallen to 50% of GPs following around 60% of recommended monitoring. This is an important reason as to why this quality standard should include a focus on medication prescribed for CB- to ensure that medication enhances/ maximises quality of life- and does increase the risk of premature morbidity.  It is assumed that people with LD will receive an annual health check- however Dr Shankar’s local audit showed that ¼ of people with a learning disability who were prescribed an antipsychotic or anticonvulsant medication (for any indication) did not have an annual health check.  In addition to this, a hypothesis is that people with a learning disability may not utilise healthcare services to the same extent compared with the general population- and that where medication is prescribed- people with LD may not have the same access to specialist and/ or community pharmacists for advice or completion of medicine usage reviews. This is an issue that we (Devon Partnership Trust) are starting to investigate with community pharmacists. Access to medication usage reviews would provide an additional check to ensure that medication was being used and monitored appropriately- and ensures the individual and/ or carers understand why they/ the person they care for is taking a specific medication (as well as understanding possible side effects and what monitoring should be offered). | Prescribing Observatory for Mental Health- UK- Audit cycle/ quality improvement work  Topic 9: Use of antipsychotics in people with Learning Disabilities  <http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/prescribingpomh/prescribingobservatorypomh.aspx>  Health Inequalities & People with Learning Disabilities in the UK: 2010  Eric Emerson  Susannah Baines  <http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf>  Devon Partnership NHS Safety Briefing: Dysphagia, Choking and Psychotropic Medication:  <http://www.devonpartnership.nhs.uk/fileadmin/user_upload/MedsMan/InternetDocs/14-001_DysphagiaChokingAndPsychotropicMeds.doc>  *Shankar et al. 2014. Annual health checks of learning disability patients on psychotropic medication (re-audit) – 593 Cornwall partnership NHS foundation trust*  [currently unpublished]  *Dr Rohit Shankar*  *Consultant in Adult Developmental Neuropsychiatry - CFT*  *Hon. Associate Professor - Exeter Medical School* |
|  | SCM 2 | Six monthly review of medications prescribed for challenging behaviour incl. aggression | Aggression and agitation often precipitate the use of psychotropic, mainly antipsychotic, medications as well as hypnotics and anxiolytics which may be prescribed intermittently (prn or as needed). These medications are not supposed to be given for more than 4 weeks but often discontinuation is difficult to achieve and thus patients remain on medications with significant long term effects for years. Investigation of prescribing practices in primary care suggests that psychotropic medications are being prescribed excessively in the absence of a diagnosis of mental disorders and usually because of challenging behaviour | Systematic review of us of psychotropic medications would benefit patients as it would reduce potential excess morbidity due to side effects such as obesity and cardiovascular disease in adults with ID who take such medications, especially associated with use of antipsychotics. It is expected that short term benefit from psychotropic medication maybe had but the benefits of long term use are equivocal. There are also additional concerns about the use of such medications in older adults with ID with or without dementia which is against current guidance. | NICE guidelines for dementia and for autism |
| 12 | SCM 1 | Reduction in the inappropriate use of medication for children and adults with learning disabilities | There is evidence that children and adults with learning disabilities are prescribed medication inappropriately | Medication should only be used to treat the condition it is licensed for. There should be regular reviews to ensure it is effective. Side effects should be managed and monitored. Poly-pharmacy should be avoided. | LD census  Post Winterbourne medication work (not yet published) |
| 13 | Royal College of Nursing | Pharmacological Interventions | To minimise risk of overreliance on medication - Pharmacological interventions should only be offered after consideration of co-existing mental or physical health problems, and in conjunction with behavioural/psychosocial interventions. | Recent literature suggests increasing national rates of prescribing psychotropic medication, particularly antipsychotic medication, for managing challenging behaviour, sometimes with no clear comorbid mental disorder diagnosis identified. Such medications have a range of short to long term adverse effects, especially increasing cardiometabolic risks. | Frighi V, Stephenson MT, Morovat A, Jolley IE, Trivella M, Dudley CA, et al. *Safety of antipsychotics in people with intellectual disability. Br J Psychiatry 2011; 199: 289–95* |
| 14 | College of Mental Health Pharmacy | Additional developmental areas of emergent practice |  | Locally (Devon Partnership Trust) we have been working with the NHS Quality Improvement team (as part of the Winterbourne Medicine Programme) to pilot a triage tool in order to target pharmaceutical medication reviews. The team that is piloting this provides additional support for people with behaviours that challenge- and the benefits of a pharmacist undertaking a review of currently prescribed medication has been demonstrated as a toll to optimise treatment with medication- even in people not currently prescribed an antipsychotic or anti-epileptic. This reminds us that whilst it is important to focus on appropriate prescribing of specific medication (i.e. antipsychotics) it is important not to lose sight of the overall picture- and a holistic medication review may result in recommended changes to current medication which may lead to an improvement in CB and reduce the need for additional medication to be initiated. This is an area for further research and development. | Local data available on request at present. Contact: [Amanda.gulbranson@nhs.net](mailto:Amanda.gulbranson@nhs.net) |
| 15 | Enfield Learning Disability Partnership Board Services | Staff Training and Support | The standards will likely highlight a skill gap in the supports and services for many people whose behaviour can be challenging. | Implementation of guidelines will require a workforce with relevant skills and aptitudes. Families of People whose Behaviour can be Challenging need also be prioritised for training and support. | Skills for Care and National Development Team for Inclusion (2013) Supporting staff working with people who challenge services. |
|  | SCM 2 | Carer (paid and family) training programmes | Paid and family carers manage people with challenging behaviour in care homes and/or supported living and in the person’s own home. Research suggests that paid carers may require further skills in order to manage challenging behaviour effectively. Similarly, family carers may have a different set of needs which should be met in order to enable them to care for a person with challenging behaviour. Often challenging behaviour is the by-product of inability to communicate or understand the person’s needs and to implement appropriate and evidence based interventions to reduce carer stress and burn-out. | Poor care adversely impacts patient quality of life and leads to placement breakdown and abuse. This has been shown in populations with dementia and with ID. A recent meta-analysis by Livingston et al (BJPsych, 2014) shows which interventions may be most beneficial to persons with dementia residing in care homes. Such interventions maybe adapted for people with ID.  The NICE guideline for challenging behaviour has found benefit in parent training interventions for younger persons with ID and aggression. However, no such evidence exists for adults with ID and aggression looked after by family carers. There is some information on Positive Behaviour Support which however, is non-specific to family carers. Therefore, such interventions urgently need more evidence for use in adults. | Please see: A systematic review of the clinical effectiveness  **and cost-effectiveness of** sensory, psychological and  behavioural interventions for managing agitation  in older adults with dementia  *Gill Livingston, Lynsey Kelly, Elanor Lewis-Holmes, Gianluca Baio,*  *Stephen Morris, Nishma Patel, Rumana Z Omar, Cornelius Katona and Claudia Cooper* |
| 16 | Royal College of Nursing | Referral – access to skilled teams for functional analysis and intervention | Children/young people with adults and learning disabilities with emerging challenging behaviour should have timely access to assessments by teams with expertise, knowledge and skills in functional analysis and teams that have a quorate multi-disciplinary composition (i.e. nursing, psychology, Occupational Therapists, Speech and Language Therapists, Psychiatry, Social Workers). | Differing referral criteria of services may mean that children/young/people fall out of services or assessments by teams are delayed until crises. Also teams have inconsistent disciplinary compositions and levels of training, so quality of assessments can vary greatly. |  |
| 18 | SCM 1 | Investment in local multi-disciplinary teams to provide positive behaviour support approaches including rapid response – for children and adults | Investment in local high quality support can prevent future high cost out of area placements – including residential schools for children, and “specialist” provision for adults | There is a lack of robust data around children. The SEND reforms provide an additional opportunity to make a difference to this group of children. School staff should be trained in PBS approaches  The post Winterbourne work and data collection, including the failure to meet concordat commitments demonstrates that the capacity and capability of local services and support (child and adult) needs to improve | LD census data 2014  CBF early Intervention paper (see above)  NAO report on Care Services for people with learning disabilities and challenging behaviour (2015) |
| 17 | Royal College of Nursing | Intervention – delivery of care (e.g. named keyworker, mutually agreed positive behaviour support plans focussing on prevention) | A service of high integrity, and continuity should offer a key worker system to coordinate the care and support detailed in mutually agreed person-centred positive behaviour support plans. | Anecdotally parent/carers report having to repeat their story over and over, and express a wish for continuity and minimal transitions. | Didden, R., Duker, P. C., & Korzilius, H. (1997). Meta-analytic study on treatment effectiveness for problem behaviours with individuals who have mental retardation. *AJMR-American Journal on Mental Retardation*, *101*(4), 387-399. |
| 19 | The Royal College of Paediatrics and Child Health | Key area for quality improvement 3 | Apart from undertaking a health assessment to discover any health issues that may contribute to, or cause, challenging behaviour, paediatric medical services should not be repeatedly accessed primarily to help manage challenging behaviour (which is instead more appropriately managed by CAMHS). | Limited access to CAMHS causes families of children with learning disabilities to repeatedly seek help from paediatric services for that behaviour. A standard could be based on frequency of hospital admissions and/or outpatient attendances to paediatric services primarily because of challenging behaviour. | Submission from Paediatric Mental Health Association, demonstrating the high use of paediatric services for challenging behaviour in children and young people with learning difficulties: |
| 20 | The Royal College of Paediatrics and Child Health | Early and timely access to CAMHS services | CAMHS generally provides children and young people (and their families), valuable help with respect to managing challenging behaviour. A multi-disciplinary approach between CAMHS, education and social care is desirable.  Impact on children and families, services and costs for health, Social care and Education of not managing these behaviours optimally | CAMHS services are limited around the country which limits timely access, yet the earlier appropriate intervention is provided, often the better the outcome.  Current gaps in CAMHS services and difficulties families and professionals describe in accessing advice and support  Confusion about the definition and barrier of ‘Mental health disorders’ and impact this has. Important to intervene before major disorder established |  |
| 21 | Royal College of Nursing | Health Inequality | With the Winterbourne review and the need to tackle premature death linked to health inequalities it became necessary to develop an outcome measure that builds on the theme of tackling health inequalities, seeing this as the lynchpin to improving health and wellbeing and delivering against the national frameworks.  NICE would find value in looking at the work of the Learning Disability Consultant Nurses Group on quality outcome measured Health Equalities Framework (HEF). The outcomes framework based on the determinants of health inequalities, which provides a way for all specialist learning disability services to agree and measure outcomes with people with learning disabilities. It can be used by 21services and by families and carers working in partnership with services to agree personalised priorities to monitor outcomes, particularly for people who may lack capacity to this so for themselves. | Measuring learning disability nursing provision is an indicator to good learning disability provision to meet people’s needs.  IHAL (Improving health and lives observatory) has a rich source of data to draw on. <http://www.improvinghealthandlives.org.uk/profiles/> | Please see work of the Learning Disability (LD) Consultant Nurses Group on quality outcome measured (HEF). - Health Equalities Framework. <http://www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf>  Gwen Moulster (South Staffordshire and Shropshire Healthcare NHS Foundation Trust) led its development and is a point of contact for this work.  [IHAL (Improving health and lives observatory)](http://www.improvinghealthandlives.org.uk/profiles/) |

1. <https://www.improvinghealthandlives.org.uk/publications/1241/People_with_Learning_Disabilities_in_England_2013> [↑](#footnote-ref-1)
2. <http://www.hscic.gov.uk/catalogue/PUB16760> [↑](#footnote-ref-2)
3. <http://www.bacdis.org.uk/publications/> [↑](#footnote-ref-3)
4. <https://www.mencap.org.uk/outofsight-report> [↑](#footnote-ref-4)
5. Griffith, G. and Hastings, R. 2013. ‘He’s hard work, but he’s worth it.’ The experience of caregivers of individuals with intellectual disabilities and challenging behaviour – A thematic synthesis of qualitative research, *Journal of Applied Research in Intellectual Disabilities*. [↑](#footnote-ref-5)
6. <http://www.nao.org.uk/report/care-services-for-people-with-learning-disabilities-and-challenging-behaviour/> [↑](#footnote-ref-6)
7. <http://www.hscic.gov.uk/catalogue/PUB16760> [↑](#footnote-ref-7)
8. Barron, D. Hassiotis, A. and Paschos, D. 2011. Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality, *Journal of Intellectual Disability Research*, 55, 9, pp.832-843. [↑](#footnote-ref-8)
9. <http://www.cqc.org.uk/content/review-learning-disability-services-1> [↑](#footnote-ref-9)
10. <http://www.bris.ac.uk/cipold/> [↑](#footnote-ref-10)
11. <http://www.cqc.org.uk/content/review-learning-disability-services-1> [↑](#footnote-ref-11)
12. <http://www.hscic.gov.uk/catalogue/PUB16760> [↑](#footnote-ref-12)
13. <http://www.cqc.org.uk/content/review-learning-disability-services-1> [↑](#footnote-ref-13)
14. <http://www.mind.org.uk/news-campaigns/campaigns/crisis-care/about-the-campaign/?ctaId=/news-campaigns/campaigns/crisis-care/crisis-care-slices/we-need-excellent-crisis-care/> [↑](#footnote-ref-14)
15. <http://www.hscic.gov.uk/catalogue/PUB16760/ld-census-initial-sep14-rep.pdf> [↑](#footnote-ref-15)
16. Paton, C. Flynn, A. Shingleton-smith, A. McIntyre, S. Bhaumik, S. Rasmussne, J. Hardy, S and Barnes T. 2011. Nature and Quality of antipsychotic prescribing practice in UK psychiatry of intellectual disability services, *Journal of Intellectual Disability Research*, 55, 7, pp.665-674. [↑](#footnote-ref-16)
17. Deb, S. Clarke, D. and Unwin, G. 2006. *Using Medication to Manage Behaviour Problems among Adults with a Learning Disability*. University of Birmingham. [↑](#footnote-ref-17)
18. Please note the 2009 guideline has been updated in 2014. <http://www.nice.org.uk/guidance/cg178> [↑](#footnote-ref-18)
19. <http://www.councilfordisabledchildren.org.uk/resources/a-generation-adrift> [↑](#footnote-ref-19)
20. <http://www.bris.ac.uk/cipold/> [↑](#footnote-ref-20)
21. http://www.nao.org.uk/report/care-services-for-people-with-learning-disabilities-and-challenging-behaviour/ [↑](#footnote-ref-21)
22. <http://pmha-uk.org/committee/health-select-committee-pmha-submission/> [↑](#footnote-ref-22)