Learning Together

A review of the quality of care provided to adults with a learning disability when admitted to hospital acutely unwell.

EXTENDED REPORT

NCEPOD

Improving the quality of healthcare

LEARNING TOGETHER

A review of the quality of care provided to adults with a learning disability who were admitted to hospital acutely unwell.

A report published by the National Confidential Enquiry into Patient Outcome and Death (2026)

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Cohort: *All patients aged 18 years and over, with a learning disability, who were admitted to hospital as an emergency between 1st July and 30th September 2024 inclusive.*

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NOTES FOR READERS

Definition of a learning disability

A learning disability is currently defined by three core criteria: a significant impairment of intellectual functioning, a significant impairment of social functioning, and both impairments arising before adulthood. While not everyone with a learning disability has a formal assessment of cognitive function, the gold standard approach would be a cognitive assessment with an assessment of adaptive functioning. For many, it is not always necessary to undertake a formal assessment e.g. most people with Down Syndrome have a learning disability at a moderate level, and to provide the support needed, knowledge of their adaptive skills is more important than knowing their level of cognitive function. There is a tool available in primary care to aid identification of a learning disability, which relies on knowledge of the person's adaptive skills, but this does not work so well in secondary care settings.[1-3]

It is important to differentiate a learning disability from a learning difficulty, which affects the way a person learns specific skills or processes information in certain areas (such as reading, writing, spelling or mathematics) but does not affect overall intelligence. Examples of learning difficulties include dyslexia and dyscalculia.[4]

It is worth noting a further potential area for confusion in terminology. 'Intellectual disability', is a term used more globally and in research, particularly the United States of America, where the term 'learning disability' would be equivalent to 'learning difficulty' in the UK. No evidence was found in this study of the term 'intellectual disability' being used.

Severity of a learning disability

Until recently it was also common to identify different levels of learning disability; mild, moderate, severe and profound, based on IQ testing. However, there is a now a move towards classifying the severity of a learning disability on social functioning. While we know this is a less evidence-based concept, we asked clinicians to estimate the severity of the learning disability so we could look at the severity and outcomes (Figure 1).

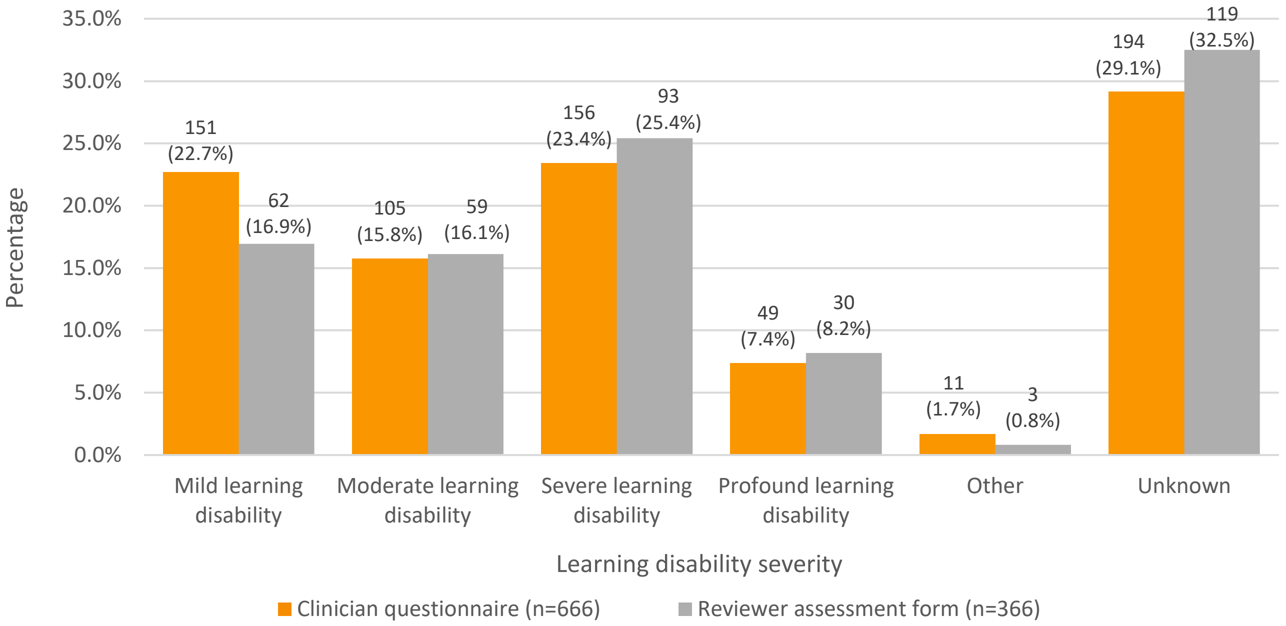

Figure 1 Learning disability severity comparing data sources

Clinician questionnaire and reviewer assessment form data

INTRODUCTION FROM OUR CHAIR

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In the UK, 2.16% of adults are believed to have a learning disability, that is around 1.5 million people.[5] Data from deaths notified to and reviewed by integrated care boards as part of ‘Learning from Lives and Deaths - people with learning Disability and Autistic people’ (LeDeR), has found that on average, people with a learning disability die 20 years younger than the general population.[6] This report adds to that work by investigating how emergency care is provided to all people with a learning disability, and not just those who died.

Recognising that a patient has a learning disability is a vital first step towards providing appropriate care. Where this has not been recognised, confusion about the definition of a learning disability and a learning difficulty may result in inconsistent identification, coding and treatment of people with a learning disability. A lack of accurate coding means that patients with a learning disability who could not be identified through hospital data may have missed being included as part of this study, or similar reviews.

Having identified that a patient has a learning disability, it is a legal requirement that reasonable adjustments, such as playing music to enable someone to remain calm, are identified and made to ensure that the healthcare provided meets the needs of the individual. These adjustments should be documented and shared to support care across all healthcare settings.

Knowing that someone has a learning disability would enable appropriate adjustments to be identified and shared at referral and start the moment they reach the hospital. Electronic alerts can be sent to the learning disability services and a standardised assessment triggered to assess the individual’s baseline function and identify what support they need. This is important as the study confirmed that many people had medical complexity and were on multiple medications. The use of up-to-date health and care passports facilitates the sharing of this information. However, opportunities to review passports were often missed and decisions regarding care were often based on limited information.

One of the most important determinants of outcome was the involvement of carers in hospital care. It was also noted that reasonable adjustments were more likely to be made if a carer was involved. However, carers themselves need support and highlighted free parking, open visiting hours, food and access to toilets on the ward as facilities that they would find most useful. Many hospitals reported the use of a carer’s passport, but few carers were aware of these.

The involvement of acute hospital learning disability teams to support patients and clinical teams also improved the quality of care provided. Although these multidisciplinary services should be available seven days a week, inevitably patients are also cared for by clinical teams without specialist training. The study found that the assessment of mental capacity was inconsistent and many clinicians lacked confidence in carrying them out. Training and upskilling in the understanding and assessment of mental capacity should be a priority.

People with a learning disability and their carers should be at the centre of decision-making about hospital care. Understanding and meeting the care needs of people with learning disabilities is everyone’s responsibility, not just that of specialist services.

I would like to thank everyone involved in the production of this report.

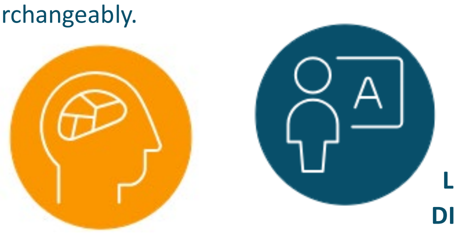
Dame Suzy Lishman, NCEPOD Chair

IMPROVING THE CARE PROVIDED TO PATIENTS WITH A LEARNING DISABILITY ADMITTED TO HOSPITAL

NCEPOD reviewed the care of adults with a diagnosed learning disability who attended/were admitted to hospital as an emergency between 1st July and 30th September 2024. Care was reviewed using 666 clinician questionnaires, 366 sets of case notes, 144 primary care questionnaires, 199 organisational questionnaires, 832 healthcare professional survey responses and 82 patient/carer surveys.

Use the correct terminology. LEARNING DISABILITY and LEARNING DIFFICULTY are not the same and using 'LD' does not help.

119/366 (32.5%) patients were described as having a learning difficulty rather than a learning disability and the two terms were often used interchangeably.



LEARNING DISABILITY

Describes a significant impairment of intellectual and social functioning, both arising before adulthood

LEARNING DIFFICULTY

Describes the way a person learns specific skills or processes information

Accurately record a person's identified learning disability in the electronic patient record/clinical notes and in learning disability registers/lists.

175/196 (89.7%) organisations reported using alerts or flags on electronic patient records. However, only **310/583 (53.2%)** patients had such alerts.

Assess and implement reasonable adjustments for patients with a learning disability – ideally proactively.

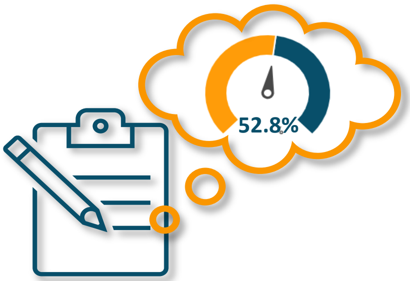
Only **292/666 (43.8%)** patients and/or their carer were asked if any reasonable adjustments were needed during the admission.

Reasonable adjustments were more likely if there was an alert on the patient's record.

Use decision support tools to aid healthcare professionals assessing mental capacity in patients with a learning disability.

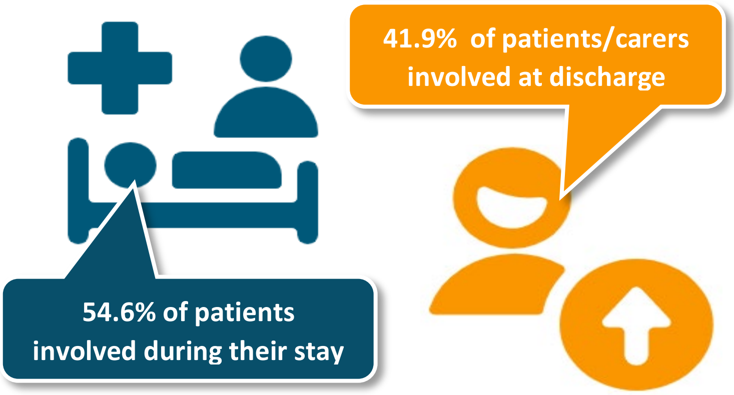
121/229 (52.8%) patients who did not have a formal assessment **should have** received one.

Only **169/277 (61.0%)** healthcare professionals reported being confident in undertaking mental capacity assessments in patients with a learning disability.



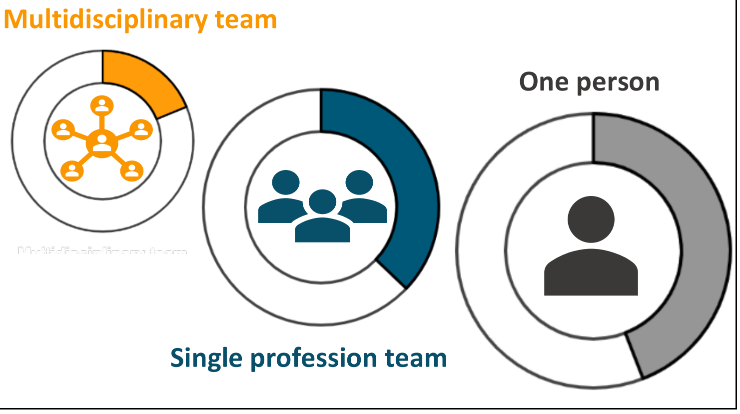
Consistently and continuously involve people with a learning disability in their care during a hospital admission.

200/366 (54.6%) patients were involved in **decisions regarding their care** in the acute setting and in **148/353 (41.9%)** cases there was **no involvement** of the patient or the patient's carer **at discharge.**



Commission equitable acute hospital learning disability services.

Only **35/186 (18.8%)** learning disability services were **multidisciplinary, 69/186 (37.1%)** were a **single profession** and **82/186 (44.1%) a single individual.**



RECOMMENDATIONS

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on. The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients. The results of such work should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards.

1	Accurately record a person's identified learning disability in the electronic patient record/clinical notes and in learning disability registers/lists. ▪ This information should be accessible across healthcare settings to ensure prompt recognition and proactive care for patients with a learning disability on arrival at hospital.
FOR ACTION BY	Integrated care boards and local commissioners in discussion with primary/community care, hospital trusts/health boards and associated learning disability services as well as electronic patient record providers.
RATIONALE FOR THE RECOMMENDATION	Diagnosis of a learning disability was not always recorded on a register/list or patient record systems/in clinical notes. In addition, patients were commonly recorded as having a learning difficulty or the terms used interchangeably. The current digital infrastructure is embedding inequity for such a vulnerable population. A digital system that can be viewed and accessed across all healthcare settings would enable a structured and proactive response to be able to meet the needs of a person with a learning disability arriving in hospital and prevent healthcare professionals repeating questions or needing to actively share information across services. There are numerous stages of a patient pathway where assessments are made and could be used to check that a learning disability is correctly recorded for future reference.
ASSOCIATED GUIDANCE	NICE QS187 LEARNING DISABILITY: CARE AND SUPPORT OF PEOPLE GROWING OLDER NHS ENGLAND: REASONABLE ADJUSTMENT FLAG NHS ENGLAND: IMPROVING IDENTIFICATION OF PEOPLE WITH A LEARNING DISABILITY GUIDANCE FOR GENERAL PRACTICE OLIVER MCGOWAN MANDATORY TRAINING PAUL RIDD LEARNING DISABILITY TRAINING
SUGGESTIONS TO AID LOCAL IMPLEMENTATION OF THIS RECOMMENDATION	

2	Assess and implement reasonable adjustments for patients with a learning disability. This should be undertaken: ▪ Proactively if the reasonable adjustments have been flagged, and in place when the patient arrives in hospital ▪ As soon as practicable after arrival/admission to hospital and be reassessed throughout the admission. *The reasonable adjustments should be recorded in the patients electronic record/notes register/list for future admission and on the person's reasonable adjustment digital flag which will be mandatory in England from September 2026.*
FOR ACTION BY	Integrated care boards and local commissioners in discussion with their hospital trusts/health boards.
RATIONALE FOR THE RECOMMENDATION	This study found that patients and their carers were often not asked about the reasonable adjustments they needed during their hospital admission. There is a legal duty to deliver reasonable adjustments for patients. Increased appointment times, a quiet waiting area and easy-read information are often offered but future commissioning needs to consider overall equity of care with a focus on preventative approaches and early healthcare for people with a learning disability. Reasonable adjustments such as support with scans could reduce diagnostic overshadowing when symptoms are misattributed to a disability.
ASSOCIATED GUIDANCE	NHS ENGLAND: REASONABLE ADJUSTMENTS NHS ENGLAND: REASONABLE ADJUSTMENT FLAG NHS ENGLAND: ACCESSIBLE INFORMATION STANDARD
SUGGESTIONS TO AID LOCAL IMPLEMENTATION OF THIS RECOMMENDATION	

3	Use decision support tools to aid healthcare professionals when assessing mental capacity in patients with a learning disability.
FOR ACTION BY	Integrated care boards and local commissioners in discussion with their hospital trusts/health boards as well as Royal Colleges and specialty associations.
RATIONALE FOR THE RECOMMENDATION	A person with a learning disability should not be presumed to lack mental capacity to make health related decisions. There was inconsistency in how mental capacity assessments and best interest decisions were made for the patients in this study. Furthermore, healthcare professionals reported a lack of confidence in assessing the mental capacity of patients with a learning disability.

ASSOCIATED GUIDANCE	NHS ENGLAND: GUIDANCE TO SUPPORT IMPLEMENTATION OF THE MENTAL CAPACITY ACT IN ACUTE TRUSTS FOR ADULTS WITH A LEARNING DISABILITY NHS ENGLAND: MENTAL CAPACITY ASSESSMENT FLOWCHART HEALTH NI GOVERNMENT: MENTAL CAPACITY ACT
SUGGESTIONS TO AID LOCAL IMPLEMENTATION OF THIS RECOMMENDATION	

4	Consistently and continuously involve people with a learning disability in their care during a hospital admission. This should be from the point of arrival through to discharge. Include: ▪ Support from carers as appropriate. ▪ Reasonable adjustments at all stages, e.g., using communication tools to support conversations.
FOR ACTION BY	Integrated care boards and local commissioners in discussion with their hospital trusts/health boards.
RATIONALE FOR THE RECOMMENDATION	The report found that people with a learning disability were inconsistently involved in decisions regarding their care. Similarly, carers were not always involved as appropriate. Carers who know the patient well are a valuable resource, but they should not be over-burdened with care duties while a patient is in hospital nor replace the nursing care.
ASSOCIATED GUIDANCE	NHS ENGLAND: INVOLVING PEOPLE WITH A LEARNING DISABILITY, AUTISTIC PEOPLE AND FAMILY CARERS NICE: NG150 SOCIAL AND COMMUNITY SUPPORT FOR CARERS DHSC: STATUTORY GUIDANCE. CARE AND SUPPORT STATUTORY GUIDANCE. PERSON CENTRED CARE AND SUPPORT PLANNING
SUGGESTIONS TO AID LOCAL IMPLEMENTATION OF THIS RECOMMENDATION	

5	Commission local learning disability support services to enable equitable access to care for patients with a learning disability who attend or who are admitted to hospital. Consider: ▪ Using multidisciplinary community learning disability services to provide an in-reach service. ▪ Upskilling all healthcare professionals to care for people with a learning disability. ▪ Locally assessing how many patients are seen annually to determine the size of the service needed. This would be aided by improved recognition and recording of patients with a learning disability (see recommendation 1).
FOR ACTION BY	Integrated care boards and local commissioners in discussion with their

	hospital trusts/health boards.
RATIONALE FOR THE RECOMMENDATION	This study highlighted that acute hospital learning disability services did not always exist and when they did, it was often just one person. This did not allow for a 24/7 service needed to care for patients admitted as an emergency. Acute hospital learning disability services provide important support to teams caring for patients with a learning disability who may have limited experience. They can advocate for and optimise communication between patients, carers and clinical teams to support day-to-day care. Input from the community learning disability team, who are likely to have known the person and supported them for many years, would be invaluable. They also have connections with primary care and other support agencies, such as accommodation support. Good liaison with the community learning disability team may also facilitate hospital discharge.
ASSOCIATED GUIDANCE	ROYAL COLLEGE OF EMERGENCY MEDICINE: LEARNING DISABILITIES TOOLKIT V2 HEALTH NI GOVERNMENT: LEARNING DISABILITY SERVICE MODEL
SUGGESTIONS TO AID LOCAL IMPLEMENTATION OF THIS RECOMMENDATION	

Key stakeholders who should take note of this report include*: all healthcare providers in all healthcare settings. Royal College of General Practitioners, Royal College of Emergency Medicine, Royal College of Physicians, Royal College of Physicians of Edinburgh, Royal College of Nursing, Royal College of Paramedics, Royal College of Surgeons of England, Royal College of Surgeons of Edinburgh, Royal College of Physicians and Surgeons of Glasgow, Association of Surgeons of Great Britain & Ireland, Royal College of Anaesthetists, Association of Anaesthetists, Royal College of Speech and Language Therapists, Chartered Society of Physiotherapy, Royal College of Occupational Therapists, Royal College of Radiologists, Independent Healthcare Providers, Royal College of Obstetricians and Gynaecologists, Royal College of Psychiatrists, Royal Pharmaceutical Society, Academy of Medical Royal Colleges, Society for Acute Medicine, specialty associations, social services, Patients Association, Learning Disability England, Down's Syndrome Association, Down Syndrome UK, MENCAP, Carers UK, Carers Trust, Carers Network, Challenging Behaviour Foundation, Foundation for People with Learning Disabilities.*

1 METHODS

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Study advisory group

A multidisciplinary group of clinicians was convened to steer the study from design to completion, define the objectives of the study and advise on the key questions. The group comprised a person with lived experience of a learning disability, healthcare professionals in emergency, intensive care and acute medicine, general practice and surgery, as well as allied health professionals and experts in the field, and healthcare professionals.

Study aims and objectives

The objectives of the study were to identify avoidable and modifiable factors associated with poor quality of care in patients with a learning disability admitted to hospital when acutely unwell.

Study population and case ascertainment

Inclusion criteria

All patients with a learning disability aged 18 years and over, who were admitted to hospital as an emergency between 1st July and 30th September 2024 inclusive. Patients were identified retrospectively using F70-F79 ICD10 codes in any position at discharge and/or learning disability registers within the acute trust/health board.

Exclusion criteria

Patients admitted as a day case, including same day emergency care (SDEC) admissions, as there would not be enough data to review.

Identification of a sample population

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the defined time period. From this initial cohort, up to six patients were randomly selected from each hospital for inclusion in the study.

Data collection

- **A clinician questionnaire** was sent to the named consultant caring for the patient.
- **A primary care questionnaire** was sent to the listed GP surgery for each included patient.
- **An organisational questionnaire** was sent to every hospital with an emergency department.
- **Copies of the case notes** were requested for the included admission for peer review by a multidisciplinary group of case reviewers.
- **Surveys** were completed anonymously by patients/carers and healthcare professionals.

Data analysis rules

- Small numbers have been suppressed if they risk identifying an individual (usually <3-5).
- Any percentage under 1% has been presented in the report as <1%.
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings, unless to compare groups within the same analysis.
- There will be variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

2 DATA RETURNED AND THE STUDY POPULATION

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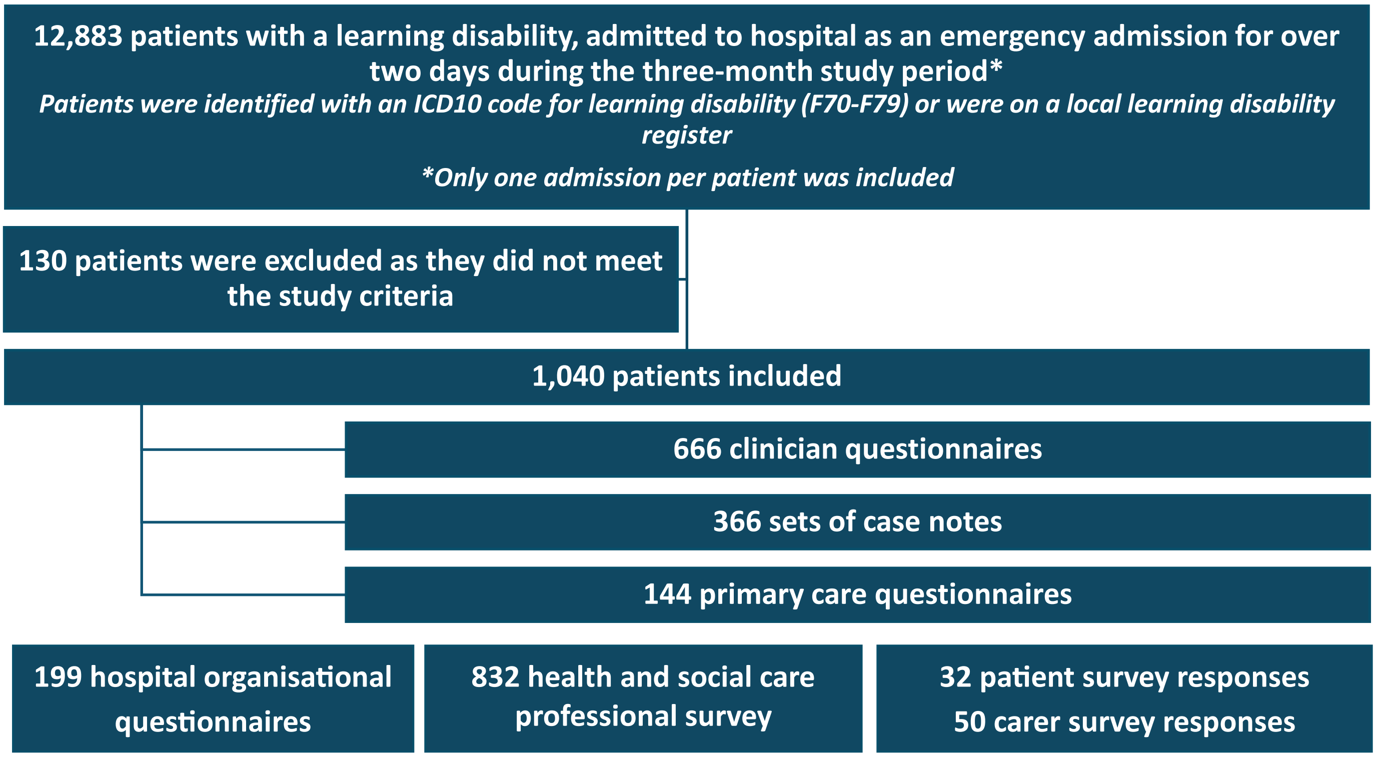
Data returns



- The mean age of the study population was 53 years, with ages ranging from 18-92 years (F2.1).
- The study population had a slightly higher proportion of White British or White – other compared with National Census data (89.2% versus 81.7%), although the ethnicity of 59/666 patients was unknown (T2.1).
- Just under half of patients in the study lived in their own homes prior to admission (288/643; 44.8%) (T2.2), of which 146/288 (50.7%) were living with parents or family and 109/288 (37.8%) lived alone.
- Most patients were receiving either full-time (279/492; 56.7%) or part-time social care support (117/492, 23.8%) (T2.3).
- There were 342/565 (60.5%) patients who had a physical disability, which was most commonly reported as a physical impairment 249/342 (72.8%) although sensory impairments were also common (T2.4 and T2.5). It is important to note that the presence or absence of a physical disability could not be recorded for 101/666 (15.2%) of the study population.
- The most common comorbidities in this patient group were neurological (291/631; 46.1%) and cardiovascular (161/631; 25.5%) conditions (T2.6).
- Most patients in the study were taking medications prior to admission to hospital (595/622; 95.7%) (unknown in 44), with 177/551 (32.1%) patients prescribed ten or more medications (T2.7). In 210/361 (58.2%) patients, these were psychotropic medications (unknown in five).
- Most patients were admitted via the emergency department (536/653; 82.1%), or via their GP (77/653; 11.8%) (T2.8).

3 IDENTIFICATION AND RECORDING OF PATIENTS WITH A LEARNING DISABILITY

DETAILED FINDINGS ABOUT THIS ARE AVAILABLE HERE

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CASE STUDY: GOOD CARE

A 45-year-old patient with a learning disability was admitted with a fractured ankle. A flag on the patient's electronic record showed that they had a severe learning disability and complex needs, so the emergency department receptionist contacted the learning disability team when the patient arrived at hospital. The team was involved throughout the patient's stay, and they were discharged home within a week.

Reviewers thought that this highlighted how early identification via an electronic flag allowed prompt specialist input and reasonable adjustments to be actioned.

CASE STUDY: ROOM FOR IMPROVEMENT

A 33-year-old patient was admitted with aspiration pneumonia. There was no clear recognition that the patient had a learning disability. Furthermore, the terms 'learning disability' and 'learning difficulty' were used interchangeably throughout the admission.

Reviewers considered that if the patient's learning disability had been properly recognised, this would have triggered involvement of the learning disability team, and the outcome could have been different.

- It was possible to identify a patient with a learning disability on the patient record system in 195/199 (98.0%) acute hospitals.
- The way in which patients with a learning disability were identified and recorded varied by organisation. A total of 175/196 (89.7%) organisations reported using alerts or flags on electronic patient records, while clinicians reported only 310/583 (53.2%) patients had such alerts (F3.1).
- 119/366 (32.5%) patients were described as having a learning difficulty rather than a learning disability and the two terms were often recorded interchangeably throughout the patients' notes. Reviewers gave numerous examples of the confusion between a learning disability and a learning difficulty. One reviewer noted "*shortened to 'LD' so not sure what they mean*" and another noted that the terms were "*used interchangeably in the same assessment by the same medic*".
- Healthcare professionals in acute settings and the community also reported that it was not easy to identify patients with a learning disability from electronic patient records or hospital systems, noting that it was slightly harder for healthcare professionals in acute care settings than for those in the community (178/415; 42.9% vs 171/301; 56.8%) (T3.1).
- A register of people with a learning disability could support a hospital response to the delivery of care. However, it was reported that only 27/195 (13.8%) acute hospitals had a register.
- More widely there were 285/809 (35.2%) health and social care survey respondents who reported that their organisation had a learning disability register, but this was much more common in community settings than in acute settings (F3.2). In addition, 297/475 (62.5%) survey respondents working in acute settings were unsure whether a register existed in their organisation. Therefore, if a register is developed, teams will need to be aware that it is available.

4 DELIVERY OF CARE

DETAILED FINDINGS ABOUT THIS ARE AVAILABLE HERE

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CASE STUDY: GOOD CARE

A 30-year-old patient with a severe learning disability, complex needs and epilepsy was admitted to hospital with pneumonia. The patient was unable to provide a history, but a full set of observations was taken when they arrived at the emergency department. Their NEWS2 was nine and they were quickly identified as rapidly deteriorating. Care was escalated appropriately and a diagnosis of sepsis secondary to pneumonia was made.

Reviewers considered that NEWS2 had enabled a rapid response and without this the seriousness of the patient's condition could have taken longer to recognise.

CASE STUDY: ROOM FOR IMPROVEMENT

A 36-year-old patient with a learning disability was admitted to hospital following a fall. The patient was discharged home despite concerns from their carers regarding the patient's overall mobility and safety. No information was given on discharge around progression or safe mobility. The patient was seen by a community physiotherapist but at the time they were alone, so it was unclear whether they were able to understand and retain the information. The patient was then readmitted following another fall in the community.

Reviewers thought learning disability team involvement could have ensured that information was provided in an accessible format and there was better communication with the patient's carers.

- Reviewers found that 50/342 (14.6%) patients did not have a full set of observations recorded on arrival at hospital, and the frequency of re-recording was inadequate for 23/310 (7.4%) patients. The most missed elements were consciousness level and respiratory rate. Pain was not recorded for 43/50 (86.0%) patients where observations had been assessed as incomplete (T4.1).
- Reviewers reported that 27/343 (7.9%) patients did not have all appropriate blood tests and/or investigations undertaken. There were clinically significant delays in the undertaking of these investigations for 26/332 (7.8%) patients, resulting in delayed treatment for ten patients (T4.2).
- Reviewers found there were delays in the delivery of care for 43/341 (12.6%) patients (unknown in 25), with 24 of these delays being attributed to the patient having a learning disability. The most common reasons for delays were difficulty tolerating interventions (11), behaviours of distress or agitation (11) and challenges with communication (9) (F4.1). Of the 24 patients who experienced a delay in the delivery of care, ten did not have any reasonable adjustments made during their admission; reviewers thought that appropriate reasonable adjustments may have prevented these delays.
- A learning disability service was reported to be present in 186/199 (93.5%) hospitals, with most services being employed directly (140/186; 75.3%) and based onsite (177/185; 95.7%). Only 35/186 (18.8%) learning disability services were multidisciplinary, with 69/186 (37.1%) uni-professional and 82/186 (44.1%) comprising a single individual, both of which were predominantly nurses (T4.3).
- A total of 127/186 (68.3%) of acute hospital learning disability services were only available during normal working hours (Monday to Friday, 0800-1800), and only 184/418 (44.0%) of health and social care professionals surveyed stated there was sufficient access to acute hospital learning disability services in the acute setting. Where the acute hospital learning disability service was not involved in the emergency department, reviewers stated that they should have been for a further 116 patients.

- Community learning disability teams provided in-reach services to support admissions in 95/188 (50.5%) acute hospitals.
- Clinicians reported that acute hospital learning disability service involvement occurred at the correct time for most patients (254/275, 92.4%). However, reviewers disagreed, reporting that input was provided at an appropriate time for 125/181 (69.1.%) patients and that patients received an appropriate level of input for only 141/336 (42.0%) patients.
- There were 169/199 (84.9%) hospitals in which a policy stated which specific clinicians should be contacted when a person with a learning disability is admitted. Responses showed that in most cases the hospital's learning disability liaison nurse was alerted (118/169; 69.8%). When a patient was on a learning disability register or had an alert in place, the learning disability service was most likely to be involved throughout the admission (165/278; 59.4% vs 62/88; 70.5%) (F4.2).
- In 123/199 (61.8%) hospitals there was mostly an informal approach to identifying patients' carers. Where present, more formal examples included alerts and documentation in the patient's electronic patient record or mention in the patient's hospital passport.
- In 105/151 (69.5%) hospitals a carer's passport was used to support identification of carers. These hospitals had carer policies that incorporated a carer passport scheme. However, only 2/36 carer survey respondents were aware of carer passports, while 38/40 thought that a carer passport would be helpful. A carer's charter was available in 91/137 (66.4%) hospitals; carers were made aware of this through the trust/health board websites (73/91) and information posters (59/91).
- A total of 151/179 (84.4%) hospitals had a carer policy. The most common components in the policy reported by the clinicians were open visiting hours (143/151; 94.7%). However, the practical help offered to carers was limited. Free parking was only offered by 69/151 (45.7%) hospitals, although a few offered concessionary parking (10/151; 6.6%), and recliner chairs (7/151; 4.6%) rather than fold-up beds (107/151; 70.9%) were offered in a small number of hospitals (F4.3).
- Clinicians documented that support was provided to the carer in 89/284 (31.3%) cases but for 227 patients it was not known, which could indicate that there was an unmet need (T4.4).
- All (39/39) carer survey respondents who were able to stay in hospital with the person they looked after found it helpful. Carers said that free parking (40/46), access to toilets on ward (33/46) and open visiting hours (32/46) would be the most helpful forms of support (F4.4).
- Patients spent a median of six days in hospital, and most were discharged back to the location they were admitted from (T4.5). Where length of stay was considered inappropriate, this tended to be related to issues with restarting or changing social care packages, or safeguarding concerns.
- Discharge summaries were provided to 118/276 (42.8%) patients who were discharged to their own home. However, discharge summaries were accessible for only 51/118 (43.2%) patients.
- Most discharge summaries included information regarding the reason for admission (306/314; 97.5%) and management/treatment (284/314; 90.4%). However, reviewers found key information was often missing from discharge summaries, specifically a lack of coding related to the learning disability (T4.6). As a result, discharge summaries were rated as poor or unacceptable in 61/314 (19.4%) cases reviewed (F4.5).
- Reviewers identified inadequate follow-up for 69/293 (23.5%) patients. The main reasons for this were a lack of acute hospital learning disability or community team involvement, and social care breakdowns often leading to hospital readmission.

5 PERSONALISED CARE

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CASE STUDY: GOOD CARE

A 72-year-old patient with a learning disability was admitted to hospital following a fall where they sustained a fractured neck of femur. The learning disability team were involved from the time of admission and there was clear evidence of communication around care planning with involvement of the surgical team. A clear plan was put into place for the patient's discharge.

Reviewers thought that this case highlighted the important role of learning disability teams to support coordination of care and discharge planning.

CASE STUDY: ROOM FOR IMPROVEMENT

A 58-year-old patient with a learning disability was admitted to hospital with urosepsis. The patient was noted to need 24-hour care. Although they were deaf and non-verbal the patient was physically mobile and independent with activities of daily living. During the admission the patient developed an aspiration pneumonia. A decision was made for no escalation of care, despite no evidence of contact with critical care. A do not attempt cardiopulmonary resuscitation decision was put in place with the primary reason being the patient's learning disability.

The reviewers felt this decision was potentially inappropriate, as it was not in keeping with the patient's lack of cardiorespiratory comorbidities and their prior level of function.

- Having a standardised approach to assessment allows clinical staff to understand the person's individual needs and take proactive action, for example ensuring that any reasonable adjustments can be made early or triggering the involvement of acute hospital learning disability services. Despite this, only 82/199 (41.2%) participating hospitals reported having a standardised admission checklist for people with a known learning disability.
- Clinicians stated checklists were used for 221/407 (54.3%) patients. However, reviewers found that only 33/342 (9.6%) case records contained evidence that a standardised checklist had been used (F5.1), and as a result, they stated that baseline care needs were not recorded for 82/356 (23.0%) patients. It was also noted that for 259 patients, clinicians completing questionnaires in the hospital were unable to determine whether a checklist was used.
- On presentation to hospital, 382/539 (70.9%) patients were accompanied by someone they knew (T5.1), most commonly a family member or partner (205/382; 53.7%) and paid carers (181/382; 47.4%) (T5.2).
- Patients with more severe learning disabilities were more likely to be accompanied by someone they knew on admission to hospital (F5.2).
- Clinicians found that there were challenges to getting a full medical history for 139/594 (23.4%) patients, especially when patients were unaccompanied (F5.3). Where challenges were identified by reviewers (91/366; 24.9%), these most commonly related to issues with communication (58/91; 63.7%) or the absence of a relative/carer to support history taking (30/91; 33.0%) (T5.3).
- Patient passports are usually created with input from someone familiar with the individual, helping to ensure personalised care that takes their needs and preferences into account. The development of a patient passport in the community ensures that vital information is available at the time of an

acute hospital admission. However, clinicians caring for the patients reported that such passports were only present for 205/666 (30.8%) patients.

- Where passports were present, most were rated as good (63/94; 67.0%) or adequate (24/94; 25.5%), although there was only evidence of the passport being used in 86/145 (59.3%) cases suggesting potential issues with either access or awareness of healthcare teams.
- According to data from the organisational questionnaire, 177/186 (95.2%) hospitals indicated that passports could be provided to patients with learning disabilities who presented without one.
- The severity of the learning disability appeared to be associated positively with the likelihood of passports being used, although they were still only present in around half of the patients with a severe or profound learning disability (F5.4).
- Diagnostic overshadowing refers to the wrong assumption that symptoms of an illness are due to an already diagnosed condition. An example would be attributing behaviours that were seen as challenging to a learning disability when they could be a reaction to abdominal pain, which in turn might be symptomatic of a physical health problem.
- Reviewers of the case notes identified diagnostic overshadowing more commonly (24/345; 7.0%) than the clinicians in the hospital where the patient was cared for (18/588; 3.1%) (T5.4), potentially highlighting a lack of awareness of the risk of diagnostic overshadowing by acute healthcare clinicians.
- Training provided to staff members was identified in 74/141 (52.5%) responses from hospitals as a gap in service provided to patients with a learning disability.
- Data from the health and social care survey showed that 379/491 (77.2%) respondents in acute hospitals received training in the care of people with learning disabilities.
- Clinicians reported that 123/460 (26.7%) patients had an advance care plan at the time of admission. The likelihood of an advance care plans being in place increased with the reported severity of learning disability.
- A total of 112/538 (20.8%) patients had a DNACPR decision in place prior to hospital admission, with 80/538 (14.9%) being put in place during the acute admission (unknown or NA in 128). Where these were created during the acute hospital admission, reviewers reported that the decision to complete a DNACPR form was potentially inappropriate for 13 patients. This was often a result of a lack of clear evidence of discussions with the patient and/or carer, or a lack of clinical information other than the presence of a learning disability.

6 REASONABLE ADJUSTMENTS

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CASE STUDY: GOOD CARE

Carers shared many relatively small adjustments that benefited those they supported. Most were practical, such as the provision of a quiet space or side room for the person they cared for. One carer said that rather than sitting in the surgical lounge with others, the person they cared for was able to wait with their carer in their own room prior to an operation, which helped them to stay calm. Others highlighted more subtle adjustments such as the positive staff response when a woman's non-verbal sister became distressed.

Reviewers thought that these were small changes that potentially had a big impact for patients, carers and staff.

CASE STUDY: ROOM FOR IMPROVEMENT

A 57-year-old patient with a learning disability was admitted with community-acquired pneumonia. There was a clinical suspicion of a pulmonary embolism (PE), but the patient refused the CT scan. There was no contact with the learning disability team and no documented assessment of mental capacity. A healthcare professional who knew the patient from a previous admission suggested an orientation to radiology as this had helped previously, but this reasonable adjustment was never actioned, and the scan was never performed. Treatment was commenced for a PE without confirmation.

Reviewers stated that as orientation to radiology had worked previously a similar approach could have helped and enabled radiological confirmation of a PE, and supported decisions on long-term anti-coagulation.

- Reasonable adjustments involve removing barriers that disadvantage people with a disability in physical environments, processes and communication. There is a legal requirement to make reasonable adjustments for people with a disability under the Equality Act 2010 and getting these adjustments right is important to make the correct diagnostic and treatment decisions for an individual.
- A policy on the use of reasonable adjustments was in place in 134/199 (67.3%) hospitals, but only 116/199 (58.3%) had a standardised approach to identify reasonable adjustments for patients with a learning disability.
- The practicalities of sharing reasonable adjustment flags varied, with many hospitals having more than one approach to identifying the needs of patients (T6.1).
- While most flags were shared digitally (81/116; 69.8%), in 39/116 (33.6%) hospitals, flags were also shared in paper notes, which inevitably could reduce staff awareness of patients' needs. The new reasonable adjustment flag, mandated in England, provides an opportunity for sharing reasonable adjustments across healthcare settings but was only mentioned by 16/116 (13.8%) hospitals.
- The Royal College of Physicians have grouped routinely available adjustments across five areas: Time, Environment, Attitude, Communication and Help (TEACH). Adjustments falling under the 'Time' and 'Help' categories were most uniformly offered by hospitals. In addition, learning disability service involvement was reported as a commonly available adjustment (T6.2).
- More than half (220/408; 53.9%) of health and social care professionals working in acute physical health hospitals reported that reasonable adjustments could be put in place routinely within their

organisation (T6.3), while less than half were of the opinion that it was easy to flag adjustments needed in the patient's record (119/265; 44.9%) (T6.4).

- Only 15/187 (8.0%) hospitals always offered clinical information and letters in accessible formats. Most hospitals (135/187; 72.2%) used accessible formats inconsistently, and there was an awareness that even if organisations comply with the standard, information may still not be accessible for people with complex needs (T6.5).
- Clinicians reported that 292/666 (43.8%) patients and/or their carers were asked if any reasonable adjustments were needed during the admission. The corresponding figure for the reviewers was lower (121/366; 33.1%) (T6.6).
- The reviewers could find documented evidence of reasonable adjustments being made for 159/366 (43.4%) patients. However, reasonable adjustments were often made inconsistently throughout the admission (77/366; 21.0%). Help (124/159; 78.0%) and Communication (90/159; 56.6%) were the most common adjustments.
- Clinicians identified reasonable adjustments that could have been made and could have helped 45/430 (10.5%) patients, whereas reviewers identified many more (139/279; 49.8%) patients who could have benefited from reasonable adjustments. Communication, including learning disability service input, was the most common reasonable adjustment identified as something that could have helped during the admission (108/139; 77.7%), this may not have been delivered due to pressures within the system (T6.7 and F6.1).
- Reviewers found that reasonable adjustments were much more likely to have been made if the carer was involved throughout the admission (69/168; 41.1% vs 3/75; 4.0%). Reviewers determined that for 107/366 (29.2%) patients, carer involvement was inconsistent (T6.8).
- From the 50 responses received from the carers survey, 22/50 felt that changes were not offered or made to meet the needs of the person they supported.
- The effective implementation of reasonable adjustments depends on an awareness of individual needs. One reviewer noted "*the carer knew the situation well; reasonable adjustments were made without a second thought and worked closely with the family*." Having a learning disability alert on the electronic patient record or a learning disability register meant that it was more likely that reasonable adjustments were made during the admission (F6.2).

7 COMMUNICATION AROUND CARE PROVIDED

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CASE STUDY: GOOD CARE

A 42-year-old patient with a profound learning disability and unable to speak was admitted with a urine infection. The patient's sibling carers were involved throughout and were able to share that when the patient was happy, they smiled and made specific sounds such as ‘woo’, but when experiencing pain would frown and shout out.

Reviewers thought that sharing these ‘soft signs’ made it easier for the clinical team to understand how the patient was feeling, enabling the delivery of more personalised care.

CASE STUDY: ROOM FOR IMPROVEMENT

A 28-year-old patient with a moderate learning disability was admitted after being hit by a car. It was advised that the patient should wear a neck support until a full assessment of their cervical spine had been completed, but the patient refused. There was no evidence that the risks of not wearing the neck support were explained.

Reviewers felt that if the risks and benefits had been shared in a way the person could understand more easily this could have helped the discussion on why a neck support was being recommended, and the patient may have made a different decision to protect their cervical spine.

Effective communication with patients is key to the delivery of excellent healthcare. Whenever possible, a person with a learning disability should be at the centre of and involved in all decisions about their care, recognising that this may not always be feasible depending on the severity of the learning disability.

- Clinicians found evidence of attempts to involve the patient and/or their carer/next of kin in decisions around their care for 553/593 (93.3%) patients (unknown in 73).
- Reviewers found that although 200/366 (54.6%) patients were involved in decisions regarding their care in the acute setting, this was often inconsistent (85/366; 23.2%). There was also inconsistent evidence of the involvement of the patients’ carers/next of kin in care decisions (T7.1).
- Carer involvement was reported to take many different forms, but this often depended on the needs of the individual and sometimes included involvement in decisions regarding mental capacity and best interest decisions (F7.1).
- Carer survey respondents felt that their role was to help the people they work with ‘understand what was happening’ while in hospital (36/39) and to be a familiar presence in what can often be a daunting environment.
- At discharge, reviewers found evidence of attempts to involve the patient in decisions regarding their care in 86/353 (24.4%) sets of notes, while there were attempts to involve the patient’s carer/next of kin in decisions for 174/353 (49.3%) patients. However, in 148/353 (41.9%) cases there were no attempts to involve the patient or the patient’s carer/next of kin at discharge.
- The Mental Capacity Act (MCA) provides the legal framework for making decisions on behalf of people who lack the capacity to make those decisions by themselves. All individuals aged 16 years and over must be treated as having decision-making capacity unless it is proven otherwise.

- A decision support tool to support mental capacity assessments was available in 177/186 (95.2%) hospitals, but only 136/188 (72.3%) had a standard operating procedure (SOP) to follow when assessing mental capacity in people with a learning disability (F7.2).
- Mental capacity decisions were reported as being recorded in most hospitals (196/199; 98.5%) (T7.2). The methods used to record these decisions varied, with 138/196 (70.4%) using electronic forms and 95/196 (48.5%) using paper forms, making accessing information difficult.
- Reviewers reported that formal mental capacity assessments were made consistently during the admission for 104/366 (28.4%) patients, inconsistently for 33/366 (9.0%) patients and not made at all for 229/366 (62.6%) patients.
- Reviewers were of the opinion that 121/229 (52.8%) patients who did not have a formal assessment of mental capacity should have received one.
- If a person is found to lack the capacity to make a specific decision in a specific timeframe, any decision made on their behalf must be in their best interests in line with the Mental Capacity Act and should be the least restrictive option to achieve the desired outcome. Clinicians reported that 161/552 (29.2%) patients had a best interest decision made during the admission.
- Reviewers identified 76/366 (20.8%) patients who refused or declined investigations or treatment.
- Sometimes is it necessary to restrict someone's liberty to keep them safe. In such instances, the Mental Capacity Act includes Deprivation of Liberty Safeguards (DoLS) to protect people and ensure that restrictions are only used when necessary. Reviewers found evidence of restrictive practice during the admission for 67/366 (18.3%) patients. The restrictive practice was not underpinned by a DoLS form in 39/67 patients.
- Under the Mental Capacity Act, if a person who lacks capacity has no family or friends to represent them, an Independent Mental Capacity Advocate (IMCA) must be involved in decisions about serious medical treatment. Patients had access to IMCAs in 193/197 (98.0%) hospitals, and this was mostly within normal working hours (142/193; 73.6%) (T7.3).
- Reviewers found that IMCAs were involved for six patients (T7.4) but also identified additional patients where IMCAs should have been involved (28/254; 11.0%) (unknown in 35).
- In total 244/648 (37.7%) patients were reviewed by a surgical team during the admission and 101/654 (15.4%) underwent surgery (T7.5). Reviewers highlighted that the mental capacity of a patient with a known learning disability should be considered before surgery and that all discussions around consent should be clearly documented.
- Both the clinicians and reviewers considered that there could be improvements in the assessment of mental capacity (F7.3). Suggestions included involving learning disability services and making reasonable adjustments so patients could understand what they were being asked.
- Although 277/475 (58.3%) health and social care survey respondents assessed mental capacity as part of their role within the acute setting (T7.6), only 169/277 (61.0%) felt confident to do so.
- Health and social care survey respondents reported wide use of decision support tools and training in mental capacity assessments (F7.4), and those who had received mental capacity assessment training within the previous two years, reported an improvement in confidence in carrying out the assessments (78/97; 80.4%).

8 OVERALL QUALITY OF CARE

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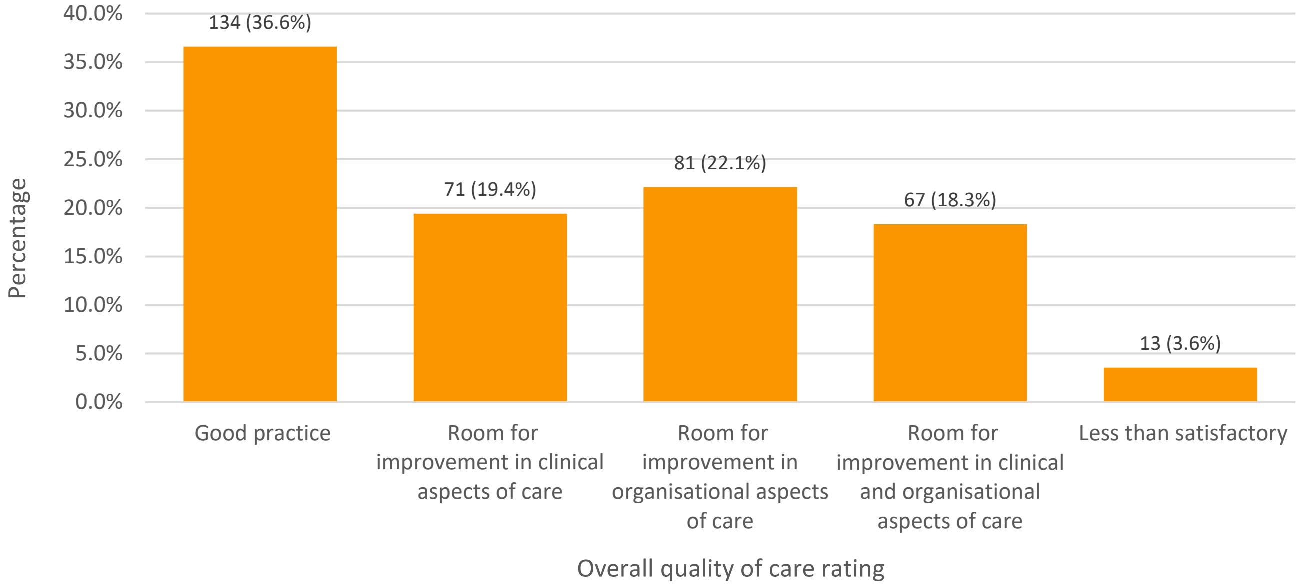
- Reviewers rated the overall quality of acute care for patients as good for 134/366 (36.6%) patients. They found room for improvement in 219/366 (59.8%) cases reviewed, and less than satisfactory care in 13/366 (3.6%) cases (F8.1).



F8.1 Assessment of overall quality of care
Reviewer assessment form data; n=366

- Clinicians completing questionnaires highlighted where improvements could have been made for patients with a learning disability admitted to hospital. These included identification of care needs at the point of admission, earlier and more consistent access to an acute hospital learning disability service, more robust approaches to the assessment of mental capacity, and greater involvement of family and carers to support the assessment and care provided to patients.
- Clinicians completing questionnaires in their hospitals believed the care was equitable for 588/626 (93.9%) patients with a learning disability. In contrast, the reviewers found that care was equitable for 251/342 (73.4%) patients. In their opinion, for 91/342 (26.6%) patients there was a deviation from the standard of care typically provided to a person of the same demographics without a learning disability (T8.1).
- Reviewers considered that the fact that a patient had a learning disability impacted on the quality of physical healthcare they received in 71/345 (20.6%) cases reviewed; in 5/77 cases there was a positive impact, while for 66/71 there was a negative impact (T8.2).
- Involvement of an acute hospital learning disability service to support the delivery of care improved the quality of care provided, leading to good practice in 87/193; 45.1% patients (F8.2).
- Care provided was more likely to be graded as good when the patient was accompanied compared to when they were alone (93/219; 42.5% vs 31/96; 32.3%) and when carers were involved throughout the admission to hospital (F8.3).