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

Recommendation no: 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.

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.	**CHAPTER 3 PAGE 13** It was possible to identify a patient with a learning disability on the patient record system in 195/199 (98.0%) acute hospitals. 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 that the two terms were often recorded interchangeably throughout the patients’ notes. 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. **CHAPTER 4 PAGE 15** 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	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

	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).	

Recommendation no: 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.

Integrated care boards and local commissioners in discussion with their hospital trusts/health boards.	**CHAPTER 4 PAGE 14** 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. **CHAPTER 6 PAGE 18** 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. 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). **CHAPTER 6 PAGE 19** 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).	NHS ENGLAND: REASONABLE ADJUSTMENTS NHS ENGLAND: REASONABLE ADJUSTMENT FLAG NHS ENGLAND: ACCESSIBLE INFORMATION STANDARD

	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. 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).	
Recommendation no: 3		
Use decision support tools to aid healthcare professionals when assessing mental capacity in patients with a learning disability.		
Integrated care boards and local commissioners in discussion with their hospital trusts/health boards as well as Royal Colleges and specialty associations.	**CHAPTER 7 PAGE 21** 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.	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

<table>
<tr><td></td><td>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).
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%).</td><td></td></tr>
<tr><td colspan="3">Recommendation no: 4</td></tr>
<tr><td colspan="3">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.</td></tr>
<tr><td>Integrated care boards and local commissioners in discussion</td><td>CHAPTER 4 PAGE 15</td><td>NHS ENGLAND:</td></tr>
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with their hospital trusts/health boards.	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. 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. **CHAPTER 5 PAGE 16** 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. **CHAPTER 5 PAGE 17** 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 all cases reviewed in this group of patients (F5.4). **CHAPTER 6 PAGE 19** 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).	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

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).

CHAPTER 7 PAGE 20

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.

CHAPTER 8 PAGE 22

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).

Recommendation no: 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).

Integrated care boards and local commissioners in discussion with their hospital trusts/health boards.	**CHAPTER 4 PAGE 14** 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 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 learning disability services in the acute setting. Where the acute learning disability service was not involved in the emergency department, reviewers stated that they should have been for a further 116 patients. **CHAPTER 4 PAGE 15** Community learning disability teams provided in-reach services to support admissions in 95/188 (50.5%) acute hospitals. Clinicians reported that acute 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%).	ROYAL COLLEGE OF EMERGENCY MEDICINE: LEARNING DISABILITIES TOOLKIT V2 HEALTH NI GOVERNMENT: LEARNING DISABILITY SERVICE MODEL

	CHAPTER 5 PAGE 17 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. **CHAPTER 6 PAGE 19** 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). **CHAPTER 8 PAGE 22** Involvement of an acute 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).	