5 PERSONALISED CARE

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

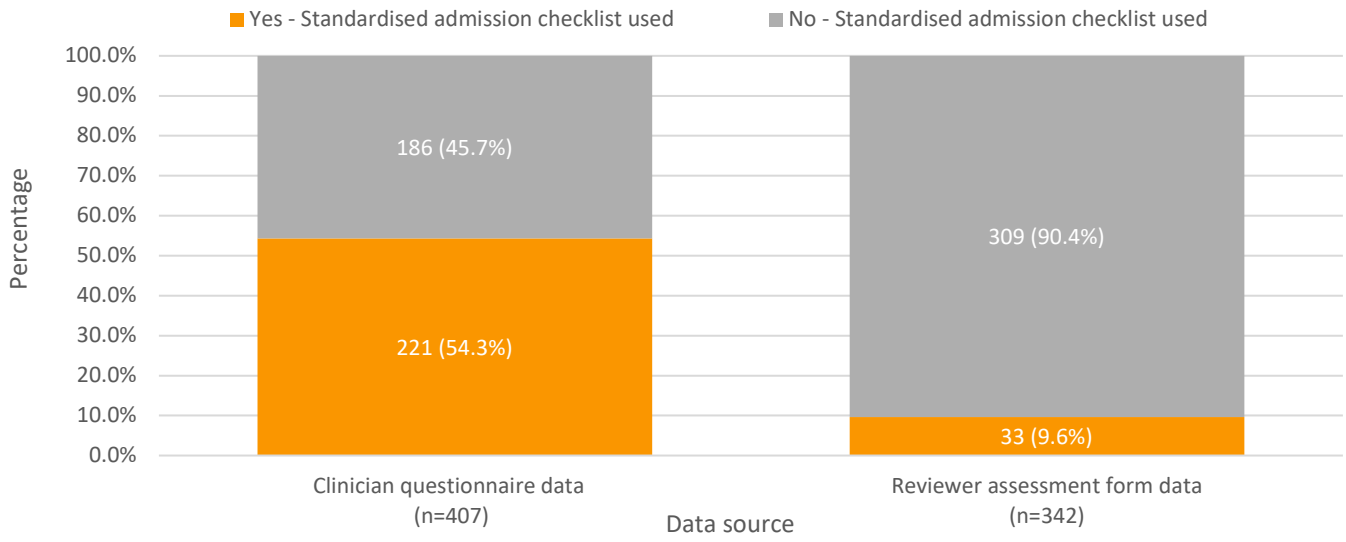
A 58-year-old patient with a learning disability was admitted to hospital with urosepsis. The patient was noted to need 24-hour care. Although they were deaf and non-verbal the patient was physically mobile and independent with activities of daily living. During the admission the patient developed an 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.

Baseline assessments

A thorough initial assessment is required as many people with a learning disability have complex medical needs and take multiple medications. The assessment can also support a patient's safety, optimise their treatment plan and maximise their outcomes while ensuring a person-centred, holistic approach. This includes an understanding of how best to communicate, what support is needed, and any known triggers or calming strategies. Learning disabilities vary widely, and individuals may have unique communication styles, sensory sensitivities or behavioural responses.[20] 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.[20]

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.



F5.1 Standardised admission checklist for learning disability used by data source

Clinician questionnaire and reviewer assessment form data

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).

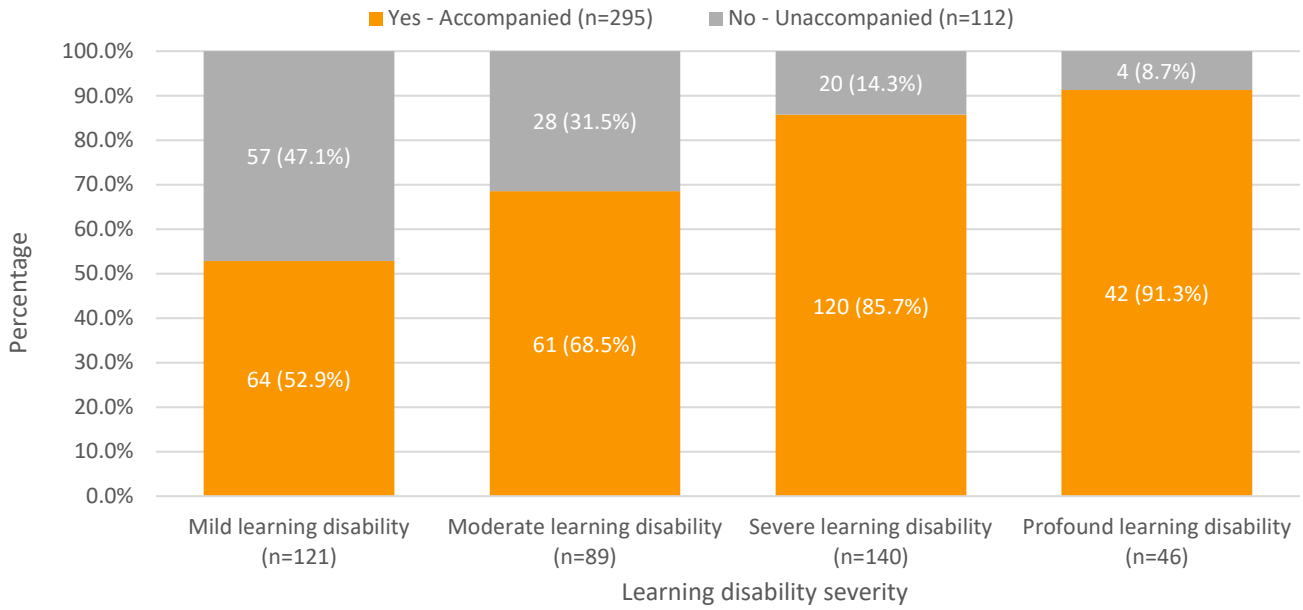
T5.1 The patient was accompanied by someone they knew	Number of patients	%
Yes	382	70.9
No	157	29.1
Subtotal	**539**	
Unknown	127	
Total	**666**	

Clinician questionnaire data

T5.2 Relationship of the accompanying person(s) to the patient	Number of patients	%
Family member/partner	205	53.7
Paid carer	181	47.4
Informal carer	3	<1
Relationship not known	3	<1
Other	18	4.7
Total	**382**	

Clinician questionnaire data. Answers may be multiple

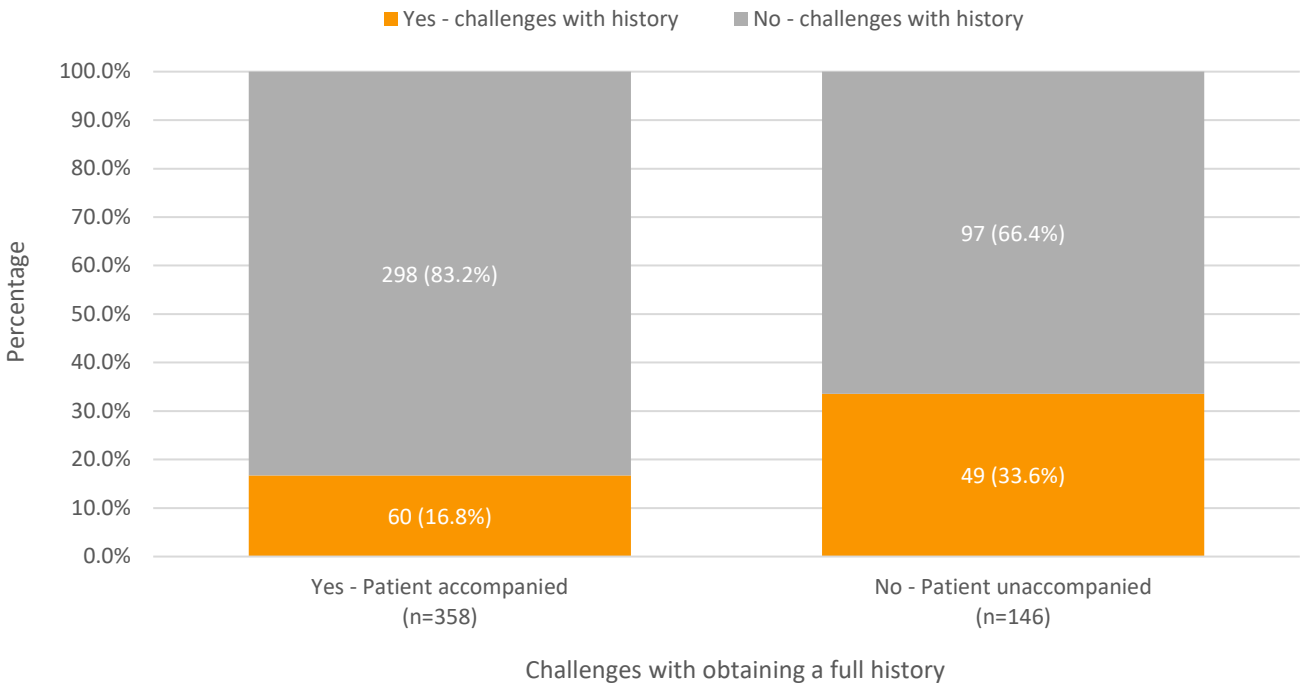
If the patient lived in their own home, they were more likely to be accompanied to hospital by a family member/partner, while patients who lived in supported living accommodation or residential homes were more likely to be accompanied by a paid carer. Patients with more severe learning disabilities were more likely to be accompanied by someone they knew on admission to hospital (F5.2).



F5.2 Learning disability severity and patient accompanied on admission

Clinician questionnaire data

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).



F5.3 Challenges with obtaining a full history of the presenting problem in patients accompanied vs unaccompanied to hospital

Clinician questionnaire data

T5.3 Challenges to obtaining a full medical history	Number of patients
Communication (e.g. non-verbal patient)	58
No carer or advocate to support with history	30
No hospital or health and care passport	29
Patient too unwell	16
Patient distress	11
No access to previous medical records	5
Clinician time/time pressures of department	5
Unfamiliar carer	4
Sensory overwhelm	2
Other	9
Total	**91**

Reviewer assessment form data. Answers may be multiple

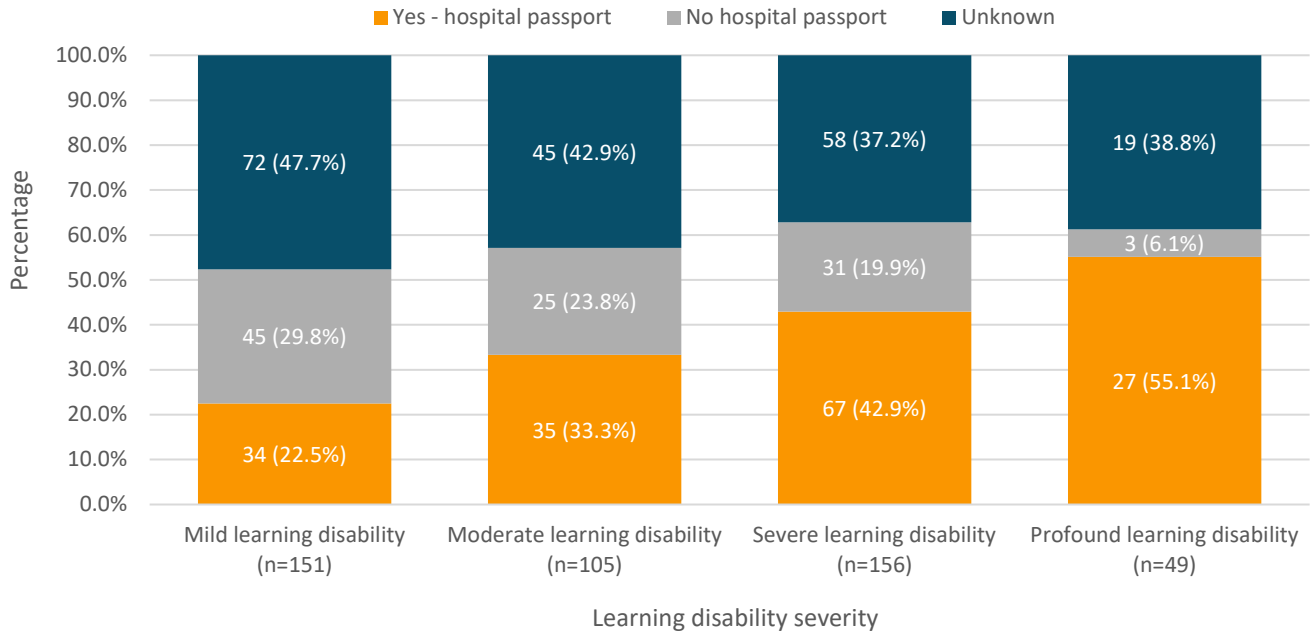
Hospital/health and care/patient passports

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. When utilised, patient passports are an effective tool for improving care in people with a learning disability but require greater awareness and standardisation of accessibility to optimise their effectiveness.[21]

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).



F5.4 Presence of a hospital passport and learning disability severity

Clinician questionnaire data

Diagnostic overshadowing

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.[18]

Diagnostic overshadowing can lead to compromised patient care and might contribute to poorer outcomes.[22] 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.

T5.4 Presence of diagnostic overshadowing	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	18	3.1	24	7.0
No	570	96.9	321	93.0
Subtotal	**588**		**345**	
Unknown	78		21	
Total	**666**		**366**	

Clinician questionnaire and reviewer assessment form data

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.

Advance care plans

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.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions

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.