BMJ Open

An audit of the quality of inpatient care for adults with learning disability in the UK

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To cite: Sheehan R, Gandesha A, Hassiotis A, *et al*. An audit of the quality of inpatient care for adults with learning disability in the UK. *BMJ Open* 2016;**6**: e010480. doi:10.1136/bmjopen-2015-010480

► Prepublication history for this paper is available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2015-010480).

Received 6 November 2015
Revised 16 March 2016
Accepted 18 March 2016

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ABSTRACT

Objectives: To audit patient hospital records to evaluate the performance of acute general and mental health services in delivering inpatient care to people with learning disability and explore the influence of organisational factors on the quality of care they deliver.

Setting: Nine acute general hospital Trusts and six mental health services.

Participants: Adults with learning disability who received inpatient hospital care between May 2013 and April 2014.

Primary and secondary outcome measures: Data on seven key indicators of high-quality care were collected from 176 patients. These covered physical health/monitoring, communication and meeting needs, capacity and decision-making, discharge planning and carer involvement. The impact of services having an electronic system for flagging patients with learning disability and employing a learning disability liaison nurse was assessed.

Results: Indicators of physical healthcare (body mass index, swallowing assessment, epilepsy risk assessment) were poorly recorded in acute general and mental health inpatient settings. Overall, only 34 (19.3%) patients received any assessment of swallowing and 12 of the 57 with epilepsy (21.1%) had an epilepsy risk assessment. For most quality indicators, there was a non-statistically significant trend for improved performance in services with a learning disability liaison nurse. The presence of an electronic flagging system showed less evidence of benefit.

Conclusions: Inpatient care for people with learning disability needs to be improved. The work gives tentative support to the role of a learning disability liaison nurse in acute general and mental health services, but further work is needed to confirm these benefits and to trial other interventions that might improve the quality and safety of care for this high-need group.

Strengths and limitations of this study

- This study uses real-life data from several hospitals to assess the quality of inpatient care people with learning disability receive.
- Audit criteria were developed through consultation with professionals and people with learning disability and their carers and therefore, reflect priorities for quality care.
- The results add to the limited quantitative evaluation of strategies to improve hospital care for people with learning disability and provide a stimulus for further investigation.
- The study may be underpowered to detect differences in care resulting from different organisational factors.
- The audit used locally collected data from a relatively small number of hospital services and might be subject to bias.

INTRODUCTION

Approximately 1% of the population has a learning disability.[1] While people with learning disability comprise a heterogeneous population, all have significant deficits in cognitive and adaptive function that arise during the developmental period (<18 years).[2] Learning disability is synonymous with 'intellectual disability', and is the term currently in widespread use in UK clinical services.

Many people with learning disability lead active and fulfilling lives, but they may also encounter difficulties and, as a group, experience higher rates of both physical and mental illness and have greater healthcare needs compared with the general population. For example, the prevalence of epilepsy in people with learning disability is approximately 25% compared with <1% in the general population[3 4] and people with learning disability are more likely to be underweight or overweight.[5 6] Although there are difficulties recognising and diagnosing psychopathology in people with intellectual disability,[7] research shows that approximately one-third have a mental disorder at any one time.[8 9]

People with learning disability may face barriers to accessing appropriate care that range from physical obstacles to those related to the way in which services are organised or delivered. Adaptations to services to cater for people with additional needs are mandated by UK law to ensure that people with impairments are not disadvantaged.[10] Adaptations might include adjustments to the physical environment, provision of accessible information, scheduling appointments at the beginning or end of clinics and allowing extra time. However, the delivery of such adjustments for people with learning disability has been found to be inconsistent,[11] leading to negative experiences of hospital admission[12 13] and substandard care that can adversely affect patient outcomes.[14 15] The recent Confidential Inquiry into premature deaths of people with learning disabilities found that men with learning disability die, on average, 13 years younger than those in the general population and women die 20 years earlier than their counterparts. Moreover, a large proportion of these deaths were classed as avoidable and amenable to change by the provision of good quality healthcare.[16]

Reducing health inequalities that people with learning disability experience has been addressed by Government policy,[17] and several practical approaches have been suggested to improve the care people with learning disability receive while in hospital.[16 18] These include the establishment of 'learning disability liaison nurse' posts and 'flagging systems' to identify patients with learning disability.

Learning disability liaison nurses typically have a number of responsibilities and work in direct patient care, to educate staff and, strategically, to interpret and enact national policies at local level.[19] There is some evidence from qualitative studies that the work of the liaison nurse is highly valued and effective.[19 20]

The development of systems to identify patients with learning disability in secondary care has been advocated by several authors.[14 16] Flagging involves adding an alert to the patient notes to inform staff of the presence of learning disability and allowing them to adapt to the process of care accordingly. However, little is known about the extent to which these initiatives have been implemented, or the impact that doing so has on the quality of inpatient care that people with learning disability receive.

In 2012, the Royal College of Psychiatrists Centre for Quality Improvement was commissioned by the Healthcare Quality Improvement Partnership to undertake a feasibility study for a national audit of inpatient care for people with learning disability. We performed a secondary analysis of data from the audit to examine steps that hospitals are taking to deliver high-quality care to people with learning disability, and examine the impact, if any, that these have on quality of care.

METHODS

Fifteen hospital Trusts were invited to take part in the feasibility study. A nominated contact at each service was required to complete an organisational checklist and to submit the results of a case-note audit using a standard data collection tool. The organisational checklist contained questions concerning the service type and facilities. The case-note audit requested demographic data and a measure of performance against 21 audit criteria that were grouped into five domains (figure 1). Audit criteria were developed following a review of relevant literature and consultation with the audit's advisory group, which included people with learning disability and their carers.[21] Anonymised data were submitted via a secure online system accessed with a unique password. All data were collected between May 2013 and April 2014. Findings of the audit have been reported,[22] and individual results sent to participating services to allow benchmarking of performance. Seven key items from the case-note audit, incorporating all elements of good quality hospital care for people with learning disability were selected for further analysis:

- Physical health/monitoring: (1) Is there a record of the patient's body mass index (BMI)/weight? (2) Did the patient receive an assessment of swallowing? (3) Do the case notes include an epilepsy risk assessment (for those with epilepsy)?
- Communication and meeting needs: (4) Is there evidence in the case notes that a health passport, or similar document, was used?
- Capacity and decision-making: (5) Is there evidence in the case notes that the patient's capacity was assessed and recorded before the first decision was made?
- Discharge planning: (6) Is there evidence in the notes that decisions about discharge involved the carer/family?
- Carer involvement: (7) Is there evidence in the case notes that the patient's informal carer had been signposted to an assessment of their current needs in advance of discharge?

Statistical analysis

Data were analysed using Stata V.13 (StataCorp. Stata Statistical Software: Release 13. College Station, Texas,

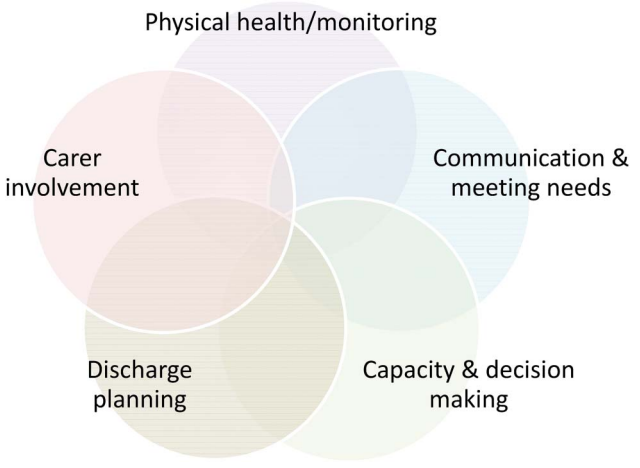

Figure 1 Domain of good quality care for people with learning disability admitted to hospital.

USA: StataCorp LP, 2013). Descriptive statistics for the cohort were generated, and compliance with each audit criterion was calculated. Where a 'not applicable' (N/A) response was an option on the audit tool, the category was collapsed, added to the 'no' group in the questions concerning whether there was a record of BMI/weight measurement, and a record of swallowing assessment. The nature of the swallowing assessment was not specified and could be expected to include any mention that the possibility of dysphagia had been considered. The 'N/A' group was excluded in questions concerning family/carers, as it is possible that people with learning disability do not have close contacts and to collapse the 'N/A' group into the 'no' responses would not be justified.

We used multivariable logistic regression to calculate the OR of a positive response in each audit question by predictor variable. Predictor variables were; the type of secondary care service (acute, general, or mental health); if the service uses an electronic system to identify patients with learning disability; and if a learning disability liaison nurse was employed. In the adjusted analysis, we accounted for age, gender and degree of intellectual disability (considered a categorical variable with two possible options (mild-moderate and severe-profound)) as possible demographic confounders. All three predictor variables were added to the adjusted regression model. In recognition of the fact that data are likely to be clustered by site, the logistic regression was conducted with robust SEs.

RESULTS

Nine acute general services and six mental health services from across England and Wales participated in the feasibility study and submitted data relating to patients admitted between May 2013 and April 2014. All, apart from the learning disability-specific mental health service, contributed an organisational checklist. An electronic system to identify patients with learning disability was present in eight of the responding services (six acute general and two mental health services). Six services (four acute general and two mental health) indicated that they employed a learning disability liaison nurse.

Results of the case-note audit

Results of the case-note audit for 176 patients were submitted. This included 109 patients in acute general services (range from each Trust was 7–15 patients) and 67 patients from mental health services (range, 5–15).

The notes audited consisted of 91 men (52%) and 85 women (48%). The mean age was 43 years (SD 16.9 years). The degree of intellectual disability was mild-moderate in 79 cases (45%), severe-profound in 37 cases (21%), and unknown in the remainder (34%). The ethnic composition was, white n=118 (67%), Asian n=22 (13%), black n=13 (7%), other/mixed n=4 (2%) and unknown in n=18 (10%).

Table 1 shows the percentage of case notes meeting each audit criterion by type of service. The strongest performance was in ensuring that family or carers were involved in discharge planning, with 84% notes having evidence that this was enacted. Weight measurement or BMI was recorded in 58% notes. Compliance with all other audit criteria was <50%. Records of swallowing assessments, epilepsy risk assessment (for those with epilepsy) and that a health passport was used fared particularly badly, with evidence of these interventions in only 19%, 21% and 24% cases, respectively.

Impact of organisational factors on delivery of care

Table 2 shows the results of the regression analysis and the influence of the predictor variables on performance on each of the audit criteria. Results significant at p<0.05 are highlighted in bold.

Service type

There was a greater likelihood of having a swallowing assessment on an acute general ward compared with mental health services (unadjusted OR 0.118, 95% CI 0.027 to 0.517, p=0.005), but this relationship did not reach statistical significance in the adjusted analysis (adjusted OR 0.212, 95% CI 0.027 to 1.701, p=0.144). Similarly, there was an indication in the unadjusted analysis that a health passport was more likely to be used on an acute general ward (unadjusted OR 0.287, 95% CI 0.093 to 0.885, p=0.030), but this relationship did not persist in the adjusted model (adjusted OR 0.441, 95% CI 0.147 to 1.323, p=0.144).

Presence of an electronic system to identify patients with learning disability

The presence of an electronic system to identify patients with learning disability did not influence most of the measured care outcomes. It was significantly associated with evidence that a carer's assessment had been offered (adjusted OR 4.458, 95% CI 1.213 to 16.381, p=0.024).

Presence of a learning disability liaison nurse

An epilepsy risk assessment was more likely where a learning disability liaison nurse was employed (adjusted OR 27.510, 95% C1.102 to 687.007, p=0.043). There was also a trend towards greater use of a health passport (or similar) in settings where a learning disability liaison nurse was employed (adjusted OR 2.042, 95% CI 0.984 to 4.241, p=0.055).

DISCUSSION

The results of the audit show that performance across a number of aspects of hospital care for people with learning disability is poor. Physical health monitoring/assessment measures were inadequately completed across settings and mirror deficiencies that have been found in

Table 1 Compliance with audit criteria

Audit question	Acute general services Yes/total (%)	Mental health services Yes/total (%)	Total Yes/total (%)
Is there a record of the patient's BMI/weight?	60/109 (55.0)	42/67 (62.7)	102/176 (58.0)
Did the patient receive a swallowing assessment?	31/109 (28.4)	3/67 (4.5)	34/176 (19.3)
Do the case notes indicate an epilepsy risk assessment?*	8/43 (18.6)	4/12 (33.3)	12/57 (21.1)
Is there evidence in the case notes that a health passport, or similar document, was used?	35/109 (32.1)	8/67 (11.9)	43/176 (24.4)
Is there evidence in the case notes that the patient's capacity was assessed and recorded before the first decision was made?	49/109 (44.0)	33/67 (49.3)	81/176 (46.0)
Is there evidence in the notes that decisions about discharge involved the carer/family?	80/94 (85.1)	49/59 (83.1)	129/153 (84.3)
Is there evidence in the case notes that the patient's informal carer had been signposted to an assessment of their current needs in advance of discharge?	29/64 (45.3)	10/41 (24.4)	39/102 (38.2)

*For those identified as having epilepsy only.
BMI, body mass index.

the physical healthcare of people with schizophrenia.[23] A swallowing assessment was completed in <20% people with learning disability. Given the prevalence of dysphagia in this group, we considered some form of swallow assessment fundamental to the care of people in an inpatient setting.[24 25] Dysphagia can have serious consequences, ranging from dehydration and undernutrition, to frequent lower respiratory tract infections secondary to aspiration and even choking and death by asphyxiation.[26] As such, it has been identified as a key risk area by the National Patient Safety Agency[27] and it is worrying that this imperative does not yet appear to have been translated to routine patient care.

We found that epilepsy risk assessments were similarly neglected. Epilepsy and convulsions are leading causes of death in people with learning disability[28] and clinical guidelines for management in this group stress the importance of epilepsy risk assessment in mitigating the risk of harm from the condition.[29 30] Highly publicised reports of recent failings in this area by secondary care services emphasise the importance of responding appropriately to this risk.[31]

There was evidence that a health passport, or similar form of patient-held health record, had been used in only a minority of cases, although we are not able to discern whether this represents a failure of the hospital to use a patient's health passport, or because no such document existed. By providing hospital staff with additional information regarding an individual's needs and contact details of their family or carers, it is believed that health passports can help overcome difficulties in communication and ensure that appropriate and individualised care is delivered. It is recommended they be completed by support staff, or the community intellectual disability teams and updated as a matter of routine. However, a recent systematic review failed to find evidence that health passports confer any health benefit in people with intellectual disability and called for more research on their effectiveness.[32]

Engaging family and carers is equally important in gathering collateral information and to avoid misdiagnosis or 'diagnostic overshadowing', where an individual's presentation is attributed to their intellectual disability rather than a treatable cause.[33] One of the positive findings of the audit was that family or carers are involved in discharge planning in the majority of cases, which we assume makes a safer discharge more likely. However, the fact that the majority of carers were not signposted to an assessment of carer need prior to discharge calls into doubt the depth and true success of carer involvement that was offered. One strength of this study is that people with learning disability and their carers, were involved in setting the audit criteria, which adds to the validity of the study in measuring the extent to which important aspects of good quality care are being provided.

The study had a number of limitations which need to be considered when interpreting the findings. First, it was not powered to detect clinically important differences in outcomes at hospitals that used different approaches to improve the quality of care that people with learning disability receive. It is therefore possible that some of the trends we observed would have attained statistical significance had the number of patients and hospitals included in the audit been higher. Second, we used a convenience sample of hospitals for the study, based on existing working relationships. The hospitals chosen were therefore a selected sample of those which had a demonstrated interest in improving care for people with learning disability. Furthermore, most of the data from the audit of acute general hospitals were collected in London, which may limit the generalisability of the results. Third, the study was observational in nature and we are therefore unable to draw firm conclusions

Table 2 Association of structural components of care with audit outcomes

	Unadjusted analysis			Adjusted analysis*		
Recorded evidence	**OR**	**95% CI for OR**	**p Value**	**OR**	**95% CI for OR**	**p Value**
BMI/weight						
MH ward vs acute ward	1.372	0.527 to 3.575	0.517	0.766	0.154 to 3.814	0.744
Electronic flagging system to identify patients with LD	0.947	0.317 to 2.830	0.923	1.134	0.324 to 3.970	0.845
LD liaison nurse employed	1.002	0.351 to 2.857	0.997	0.978	0.371 to 2.574	0.964
Swallowing assessment						
MH ward vs acute ward	0.118	0.027 to 0.517	**0.005**	0.212	0.027 to 1.701	0.144
Electronic system to identify patients with LD	2.018	0.442 to 9.210	0.365	1.001	0.192 to 5.193	0.999
LD liaison nurse employed	2.643	0.615 to 11.351	0.191	2.576	0.781 to 8.494	0.120
Epilepsy risk assessment						
MH ward vs acute ward	1.750	0.170 to 17.959	0.638	0.176	0.004 to 7.546	0.3695
Electronic system to identify patients with LD	1.670	0.126 to 22.070	0.697	1.139	0.130 to 9.959	0.906
LD liaison nurse employed	9.321	0.955 to 90.957	0.055	27.510	1.102 to 687.007	**0.043**
Use of health passport						
MH ward vs acute ward	0.287	0.093 to 0.885	**0.030**	0.441	0.147 to 1.323	0.144
Electronic system to identify patients with LD	1.457	0.523 to 4.062	0.472	1.014	0.492 to 2.088	0.970
LD liaison nurse employed	2.156	0.870 to 5.342	0.097	2.042	0.984 to 4.241	0.055
Assessment of capacity						
MH ward vs acute ward	1.233	0.426 to 3.567	0.699	1.653	0.400 to 6.825	0.487
Electronic system to identify patients with LD	1.440	0.423 to 4.901	0.560	2.146	0.717 to 6.429	0.172
LD liaison nurse employed	1.746	0.585 to 5.215	0.318	1.950	0.672 to 5.660	0.220
Carer involvement in discharge planning						
MH ward vs acute ward	0.858	0.371 to 1.983	0.719	0.720	0.100 to 5.176	0.744
Electronic system to identify patients with LD	1.991	0.831 to 4.772	0.122	1.822	0.717 to 4.631	0.208
LD liaison nurse employed	1.156	0.451 to 2.962	0.763	1.085	0.417 to 2.822	0.867
Current needs discussed with carer						
MH ward vs acute ward	0.389	0.085 to 1.780	0.224	0.573	0.119 to 2.749	0.487
Electronic system to identify patients with LD	5.159	1.338 to 19.896	**0.017**	4.458	1.213 to 16.381	**0.024**
LD liaison nurse employed	3.286	0.689 to 15.678	0.136	2.948	0.742 to 11.704	0.124

*Analysis adjusted for age, gender and degree of LD (collapsed to mild-moderate or severe-profound) and the three variables being tested.
BMI, body mass index; LD, learning disability; MH, mental health.

about the direction of relationships found. It is possible that hospitals which were concerned about quality of care for people with learning disability provided high standards or care, employed flagging systems and employed liaison nurses (rather than liaison nurses or flagging systems leading to higher quality care). Longitudinal studies, with data collection before and after changes in hospital processes are necessary to determine which elements of hospital structure are associated with greatest benefit. Fourth, the results were submitted independently by different staff from each site. It might be that these staff interpreted questions differently between sites (eg, what constitutes evidence of carer/family involvement in discharge planning), or that they missed evidence of outcomes and under-reported achievement. To investigate this possibility, a sample of case notes was audited by a second, independent rater. The κ statistic for agreement between raters on questions we analysed ranged from 0.36 to 0.88, suggesting moderate to excellent agreement in most questions.[34] Responses to the organisational checklist were not validated and as the audit was based on review of patient notes, activity that was undertaken but not documented would not have been measured. However, this would be an important finding in itself, since inadequate documentation should also be addressed. Fifth, although there were instructions to audit consecutive case notes of people with learning disability, we cannot rule out selection bias in whose notes were chosen to be audited. Last, we investigated the impact of care processes which we assumed linked to our chosen outcomes, but this might not be the case. Some of the audit criteria, such as whether a swallow assessment or epilepsy risk assessment had been conducted might not directly map to proximal outcomes. However, we believe that there is sufficient justification for these assessments in people with learning disability and that hospital admission is an opportunity to undertake such assessments, the results of which can inform community care planning after discharge and are likely to translate into improved longer term outcomes.

Physical health assessments showed a tendency in the adjusted analysis to be more likely to be performed on acute general than mental health wards, although the relationships did not reach statistical significance. The physical health assessments we chose are basic elements of care for people with learning disability, do not require technical expertise or specialist equipment and

should be equally available in any inpatient setting. People with learning disability admitted to psychiatric wards have been shown to have high rates of medical problems, underlining the importance of providing access to good-quality physical healthcare, even when psychiatric issues are the primary reason for admission.[35]

The ability of a flagging system to lead to improvements in the care of people with learning disability in hospitals is limited by the fact that only a minority of those with a learning disability are known to statutory services.[36] Hence, those without a formal diagnosis may remain 'invisible' and do not receive adapted care. Addressing this will require improved education among frontline staff and ready access to specialist diagnostic assessments. Furthermore, a flagging system should do more than simply make staff aware of a person with learning disability and, ideally, will link to local or national guidelines for managing people with learning disability and direct professionals in providing appropriately adapted care.

There are several reasons why deployment of a learning disability liaison nurse may have a positive impact on the quality of care that people with learning disability receive in hospital, including their role as an advocate, facilitating reasonable adjustments, mediating between services and professionals, and enhancing communication.[19] Learning disability liaison nurses also have a crucial role in educating hospital practitioners who provide most of the direct care for patients. Although the ORs suggest an effect of the liaison nurse in improving the care process, most failed to reach statistical significance. The role of the learning disability liaison nurse is relatively new and there may be different models of liaison work not captured by our simple categorisation. A recent Canadian study has demonstrated the value of nursing assessments in identifying medical concerns that would otherwise have been overlooked in people with learning disability referred to psychiatric clinics.[37] It may be possible for community learning disability nurses to provide input to patients, although this risks diluting the role. Another potential means by which the objectives of the learning disability liaison nurse can be achieved is to integrate the role within the newly developed Rapid, Assessment, Interface and Discharge (RAID) model of providing psychiatric liaison services to acute general hospitals.[38]

This study provides a contemporary description of the performance of acute and mental health services in providing care to people with learning disability. It adds to the limited evidence base addressing organisational factors that might influence the care outcomes. The results should go some way to improving the hospital care that people with learning disability receive and into directing future resources towards those changes that work. There is a suggestion that the presence of a learning disability liaison nurse improves the hospital care of people with learning disability, but our study seems to have been underpowered to make firm conclusions. Future research should use larger samples and prospectively examine a wider range of organisational factors, such as the availability of accessible information or access to specialist advice regarding the Mental Capacity Act, which might improve the quality and safety of care for people with learning disability who are admitted to hospital.

Our findings corroborate those of previous studies and indicate that hospital care for people with intellectual disability needs to be improved. Learning disability liaison nurses may be one way in which this can be achieved.

Contributors MJC, MK, GJ, AH, AG, PG, RC and IH contributed in the study conception and design. AG, PG, RS and RC contributed in data acquisition and management. RS and MB contributed to statistical analysis. RS drafted the manuscript. All authors have contributed by critically reviewing the manuscript.

Funding The feasibility study for the National Audit of Learning Disability is managed by the Royal College of Psychiatrists' College Centre for Quality Improvement. It is commissioned by the Healthcare Quality Improvement Partnership as part of the National Clinical Audit and Patient Outcomes Programme. The views, opinions and content of this publication this are those of the authors and not necessarily the views, opinions or policies of the NHS, or the Department of Health.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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BMJ Open 2016 6:
doi: 10.1136/bmjopen-2015-010480