REVIEW

Promoting the health, safety and welfare of adults with learning disabilities in acute care settings: a structured literature review

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Aims and objectives. To present the findings of a structured literature review that aimed to identify the influences on the health, safety and welfare of adults with learning disabilities in acute hospitals.

Background. There is increasing evidence regarding the inadequacy of care for people with learning disabilities in acute care settings. However, few studies have specifically addressed their health, safety and welfare in such contexts.

Design. Four key electronic databases (Medline; PsycINFO; British Nursing Index and archive; Cumulative Index to Nursing and Allied Health Literature) were searched for relevant literature published between 2000 and 2011.

Methods. Publications assessed as meeting the inclusion criteria were retrieved in full. Data were extracted regarding methods used; primary aims of the study being reported; and key findings.

Results. Of the 3505 papers identified in the initial search, eight met the inclusion criteria. Analysis revealed six areas of influence on the health, safety and welfare of adults with learning disabilities in acute hospitals: care provision (meeting health and personal needs); communication; staff attitudes; staff knowledge; supporters; and carers (valuing their role); physical environment.

Conclusions. We represent these six areas diagrammatically, as concentric rings. These influence on health, safety and welfare form an inner (direct) layer and an outer (indirect) layer consisting of liaison services and education/training. This new conceptualisation of influences as being multi-layered assists in the identification of similarly multi-layered improvement strategies.

Relevance to clinical practice. Adults with learning disabilities can exert their own influence on health, safety and welfare and should be supported to make decisions about their own care. More broadly they should be involved with policy development, nurse education and research. This can be achieved through inclusive approaches, for example, inviting people with learning disabilities to input into nursing curricula or to engage in research as coinvestigators.

Key words: acute care, health, intellectual disabilities, learning disabilities, literature review, nursing, safety, secondary care, welfare

Introduction

There is significant evidence that many people with a learning disability – an irreversible lifelong condition that starts at or around birth that comprises a significant global intel-lectual impairment with a functional IQ of < 70 and impairment of adaptive behaviour (Brown *et al.* 2010) – have greater health needs than the general population (Brown 2005, Disability Rights Commission 2006). Concurrent disabilities such as epilepsy, cerebral palsy and

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mental illness are common (Brown & Censullo 2008), which increase the likelihood of requiring contact with health services by almost twofold, compared to the rest of the population (Brown & MacArthur 2006). Paradoxically, however, people with learning disabilities are likely to have higher levels of unmet health needs (Campbell 2007, Kent 2008).

There is mounting empirical evidence regarding the inadequacy of secondary care for people with learning disabilities (Cumella & Martin 2004, Alborz *et al.* 2005, Mencap 2007, Gibbs *et al.* 2008, Backer *et al.* 2009, Webber *et al.* 2010). Indifference, ignorance and lack of education and training among doctors and nurses (Mencap 2011); systemic institutional discrimination (Michael 2008); and overall breaches of human rights (House of Commons & House of Lords: Joint Committee on Human Rights 2008) appear to be endemic.

The significant health needs of people with learning disabilities, coupled with enduring deficits in hospital care, make the need for further research more pressing (Brown & MacArthur 2006, Brown *et al.* 2010). However, this is an under-researched area that is only beginning to attract attention. Reviews of evidence have focussed on access, rather than provision of services (Alborz *et al.* 2005, Brown & Censullo 2008, Backer *et al.* 2009). Moreover, rather than focusing specifically on secondary care, many studies include community and non-health services, for example Alborz *et al.* (2005), Melville *et al.* (2005) and Jones *et al.* (2008). Serious injury and death, however, are also likely to occur when people with learning disabilities are admitted to hospital. To address the gap in knowledge, we undertook a review of empirical evidence regarding the promotion of health, safety and welfare of adults with learning disabilities in acute care settings. The purpose of this article is to report the findings of the review. Learning disability affects the people across the globe, and the issues we discuss are likely to transcend geographical boundaries. Thus, the article holds international relevance.

The review

Aim

The aim was to understand the factors that influence the health, safety and welfare of adults with learning disabilities in acute care settings. The review questions were:

1 What are the influences in acute care settings that promote or compromise the (1) health; (2) safety; and (3) welfare of adults with learning disabilities?

2 What strategies exist to promote the (1) health; (2) safety; and (3) welfare of adults with learning disabilities in acute care settings?

3 What are the implications for future research, policy and practice in this area?

Design

To address the research questions, we conducted a structured review of the empirical literature.

Search methods

Relevant published literature was identified by searching four key electronic databases (Medline; PsycINFO; BNI and archive; CinAHL). Search strings were developed for each database according to the following search architecture (see Table 1 for a detailed example of the search string used to search PsycINFO and BNI):

1 Safety/welfare subject headings and free text terms
2 Learning disability subject headings and free text terms
3 1 and 2.

The search took place during March 2011. Where more than one database was searched simultaneously, results were de-duplicated. No limits or filters were applied. Titles and abstracts of the publications found by this search strategy were independently scrutinised by two of the authors (CB-J & SM). Decisions regarding whether to include or exclude each publication were made according to clearly formulated criteria (Table 2).

Search outcome

Those publications assessed as meeting the inclusion criteria were retrieved in full. The reference lists of these publications were searched to identify any further publications. Two members of the research team (CB-J & SM) independently examined full-text copies of all selected articles. Consensus was then reached by consultation with the rest of the team regarding the stepwise approach that led to the included article (See Fig 1).

Quality appraisal

Assessing the methodological quality of qualitative studies using composite scales has been hotly debated and contested (Emerson *et al.* 1990). We therefore performed a global assessment of study quality, dichotimised according to whether it appears to be 'strong' or 'weak' (see Table 4). Strong studies are likely to include, amongst other things,

Table 1 Search strings used for search of PsycINFO and BNI and archive showing the number of publications for each string

Search strings for PsycINFO and BNI and archive (number of publications)

1 exp Safety Management/ or exp Safety/ (51,966)
2 exp Risk Management/ (151,314)
3 exp Patient Advocacy/ (23,998)
4 exp 'Wounds and Injuries'/ (586,481)
5 exp Self-Injurious Behavior/ (47,459)
6 exp Accidents/ (131,852)
7 exp Violence/ (103,931)
8 exp Restraint, Physical/ (11,341)
9 exp Accident Prevention/ (48,516)
10 exp Abuse Reporting/ or exp 'Abuse of Power'/ or exp Emotional Abuse/ or exp Physical Abuse/ or exp Sexual Abuse/ or exp Patient Abuse/ or exp Verbal Abuse/ (40,237)
11 exp Injuries/ (610,839)
12 exp patient violence/ (901)
13 exp Risk Assessment/ (130,822)
14 exp Physical Restraint/ (11,341)
15 exp Learning Disabilities: Abuse/ (59)
16 exp Patients: Welfare/ (1803)
17 exp 'Seclusion and Restraint'/ (446)
18 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 (1,013,443)
19 exp Learning Disorders/ (43,305)
20 exp Mental Retardation/ (108,552)
21 exp Developmental Disabilities/ (20,998)
22 exp Special Education/ (31,684)
23 exp Learning Disabilities/ (41,050)
24 exp Mental Retardation/ (108,552)
25 exp Special Needs/ (2363)
26 exp Down's Syndrome/ (22,504)
27 exp 'Mental Retardation (Attitudes Toward)'/ (690)
28 exp Mild Mental Retardation/ (3741)
29 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 (189,077)
30 exp Hospitals/ (184,220)
31 exp Inpatients/ (15,910)
32 exp Hospitalization/ (141,089)
33 exp Patients/ (124,297)
34 inpatient.mp. (49,453)
35 patient.mp. [mp=ps, rs, ti, ot, ab, nm, hw, ui, tc, id] (1,601,440)
36 exp Hospitalized Patients/ (8917)
37 exp Partial Hospitalization/ (5886)
38 exp Hospitals, General/ (9443)
39 exp Hospitals, Community/ (9320)
40 exp Hospitals, Private/ (11,886)
41 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 (1,901,480)
42 18 and 29 and 41 (1535)
43 remove duplicates from 42 (1502)

clear exposition of methods of data collection and analysis, triangulation of data, respondent validation and reflexivity. We also considered the nature of the evidence reported in the qualitative studies and assessed these in terms of the 'typologies' of their findings as described by Sandelowski and Barroso (2003). These authors suggest that findings of qualitative studies can be classified on a continuum of data transformation, from findings that are not qualitative (no finding, topical survey), to ones that are exploratory (thematic survey), descriptive (conceptual/thematic description) or explanatory (interpretive explanation). Given that the typologies are conceptualised as a continuum, it is possible for a study's findings to be rated at the junction between two categories (Table 3).

Data abstraction

Key study parameters were examined and summarised in tabular form, focusing primarily on overall methodological rigour of the included studies. Data were extracted from included publications regarding the methods used; the primary aims of the study being reported; and key findings related to our research questions.

Synthesis

A synthesis of study data pertinent to each of the review questions was performed. The synthesis included the categorisation of relevant study findings.
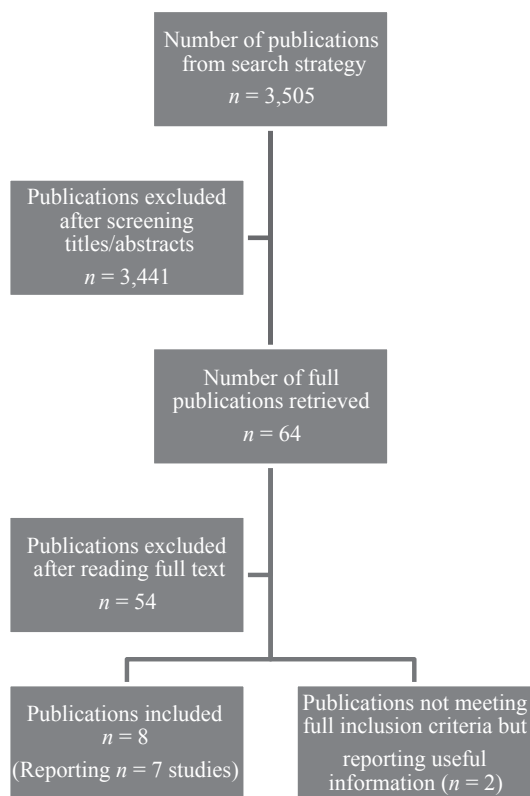
Results

Eight publications met all inclusion criteria. Details of the included articles are shown in Table 4. Two of these publications (Sowney & Barr 2006, 2007) report on the same study (although the two publications report selectively different findings). Thus, seven studies in total were included in this review. All seven studies adopted qualitative methods, although Iacono and Davis (2003) also conducted a questionnaire survey. Two studies (Cumella & Martin 2004, Brown & MacArthur 2006) collected data at a conference event. Five studies were conducted in the UK, with the remaining two conducted in Australia. Collectively, the articles reported a range of stakeholder perspectives, specifically, healthcare professionals (Hannon 2004, Brown & MacArthur 2006, Sowney & Barr 2006, 2007, Webber *et al.* 2010) and adults with learning disability and their parents, carers and supporters (Iacono & Davis 2003, Cumella & Martin 2004, Hannon 2004, Brown & MacArthur 2006, Gibbs *et al.* 2008).

Whilst eight publications were included in this review, a further two (Glasby 2002, McMurray & Beebee 2007) were deemed to be of relevance. Although eligible for

Table 2 Criteria for including and excluding publications in the review

	Criteria
Include if publication	• Focuses on adults with learning difficulties • Focuses on acute inpatient general hospital or emergency department settings • Reports data/issues pertinent to health, welfare or safety whilst in the general hospital setting • Reports empirical data whether quantitative (e.g. RCT, cohort, case–control, interrupted time series) or qualitative (e.g. in-depth interview, focus group, ethnography)
Exclude if publication	• Does not include a sufficient focus on people with learning difficulties • Is not primarily focused on adults • Is not primarily focused on general hospital settings • Is concerned mainly with access issues • Is focused on psychiatric/learning difficulty in-patient settings • Is not empirical

Number of publications from search strategy
n = 3,505

Publications excluded after screening titles/abstracts
n = 3,441

Number of full publications retrieved
n = 64

Publications excluded after reading full text
n = 54

Publications included
n = 8
(Reporting *n* = 7 studies)

Publications not meeting full inclusion criteria but reporting useful information (*n* = 2)

Figure 1 Selection of included studies.

exclusion rather than inclusion (due to failure to fully report empirical methods), the studies provide useful information to help answer the review questions and are

therefore integrated into the discussion. Similarly, the substantial grey literature (charters, reports and professional practice guidance) was excluded from the review. However, because of the pertinence of this literature, we have used it extensively in the discussion to triangulate against the review findings.

Analysis revealed six areas of influence: care provision (meeting health and personal needs); communication; staff attitudes; staff knowledge; supporters and carers (valuing their role); physical environment (see Table 5). The six areas are mapped to the research questions as represented in tabular form (Table 6). Findings can be represented as concentric layers of influence (Figure 2) that operate in an inward direction upon the person with learning disabilities.

Care provision

Six studies highlighted the issue of care provision, with significant emphasis on inadequate care. Iacono and Davis (2003) reported that people in their study did not get enough to eat (13%) or drink (18%), and almost half of the people who needed special eating utensils did not have access to these. Similarly, patients had not been given fluids (Gibbs *et al.* 2008), had been presented with a written menu that they did not understand (Cumella & Martin 2004), or had food removed uneaten (Webber *et al.* 2010). Neglect of toileting needs was also highlighted. Thirty-nine per cent of patients in the study by Iacono and Davis (2003) could not get to the toilet when needed, and similarly, Webber *et al.* (2010) reported that continent adults with learning disabilities were given continence pads, rather than taken to the toilet.

Failing to obtain help moving from bed was experienced by 11% of people in the study by Iacono and Davis (2003). Such lack of assistance may explain why one person in the study by Gibbs *et al.* (2008) was reported to have been injured by bed sides. Lack of adapted facilities meant that one patient in the study by Cumella and Martin spent six weeks in hospital without a bath. Moreover, unresponsive staff resulted in inadequate management of bed sores and failure to feed patients (Cumella & Martin 2004). However, among these largely negative experiences, there were some positive practices. For example, a woman with learning disability recounted how a nurse stayed with her while she was having a bath in case she slipped (Iacono & Davis 2003).

In terms of treatment, care of adults with learning disabilities in hospitals is often suboptimal. Cumella and Martin (2004) reported that people with learning disability in their study received inferior quality of medical treatment

Table 3 Global assessment of study quality and typologies of study findings of the seven qualitative studies included

Study	Global assessment of study quality	Typology of study findings				
Qualitative studies		No findings	Topical survey	Thematic survey	Conceptual thematic description	Interpretive explanation
Iacono	Weak			<———>		
Cumella	Weak		←—	—>		
Hannon	Weak		←—	—>		
Brown	Weak		←—	—>		
Sowney	Weak			<———>		
Gibbs	Strong			←—	—>	
Webber	Strong			<———>		

including lack of attention to epilepsy and failure to prescribe appropriate medication. Similarly, 12% of people in the study by Iacono and Davis (2003) did not obtain the correct medication, and 22% did not obtain their medication on time. Overall, most articles highlighted a picture of neglected treatment needs. However, this needs to be tempered by the findings of Hannon (2004) who reported that service users in their study had all received appropriate treatment.

There are strategies to overcome such challenges. Brown and MacArthur (2006) argue that specialist equipment aids and adaptation are necessary to ensure appropriate care. Hospitals could consider a central store of such equipment (Cumella & Martin 2004). Assessment of specific issues or problems such as pain and distress for such patients can be challenging, but assessment tools such as the Disability Distress Assessment Tool are being developed and validated (Brown & MacArthur 2006). Similarly, pain scales can be used, particularly in combination with information provided by carers or relatives (Sowney & Barr 2006).

Communication

Communication was highlighted as a core issue in all but one of the articles. There are a number of concerns. People with learning disabilities frequently have difficulty communicating their needs. For example, of the 119 people with recent hospital experiences in Iacono and Davis' (2003) study, 51 were unable to convey their needs to staff. Similarly, they do not always understand healthcare professionals (Gibbs *et al.* 2008), and the use of jargon exacerbates this problem (Hannon 2004). From the perspective of nurses, Sowney and Barr (2007) report that many have difficulty understanding non-verbal communication of people with learning disabilities, particularly when assessing pain.

Factors associated with poor communication include a rushed environment (of an emergency department); time constraints; and inadequate documentation accompanying the patient (Sowney & Barr 2007). Yet again, the situation is not solely negative. Iacono and Davis (2003) report that most people in their study were given an explanation for why they had been in hospital and what to do after discharge. Similarly, Hannon (2004) reported on the largely positive aspects of communication.

Cumella and Martin's study (2004) highlighted several strategies regarding the preparation of people with learning disabilities for admission (where possible) using resources such as videos and accessible booklets. Improving information about choices whilst in hospital was also discussed using, for example, a communication passport (Cumella & Martin 2004, Brown & MacArthur 2006), augmentative and alternative communication (AAC) or pictures/symbols to help with decisions such as meal choice (Cumella & Martin 2004). Similarly, participants in the study by Brown and MacArthur (2006) suggested several aids to communication, such as health advice sheets, books, CDs and a key ring with symbols. In relation to emergency department attendance, Sowney and Barr (2007) suggest that where possible carers should make contact, outlining any special needs or circumstances. It is then incumbent upon nursing staff to develop appropriate plans for the assessment and care of the person's needs (Sowney & Barr 2007).

Staff attitudes

It is clear from this review that discrimination towards people with learning disabilities is endemic. Gibbs *et al.* (2008) reported that carers had heard negative comments about those they care for and suspected that this was discrimination. Similarly, participants in Iacono and Davis' (2003)

Table 4 Details of the seven studies included in the review

Study (first author)	Year	Country of study	Study type/s	Study participants	Study purpose/aims
Iacono	2003	Australia	*Qualitative and Quantitative*: Questionnaire survey with follow-up in-depth interviews	Questionnaire respondents: 328 inpatients from three Victorian style institutions, 119 of whom had attended a general hospital in the previous year. Follow-up in-depth interviews with nine people concerning eight patients; one with an intellectual disability; five with cerebral palsy; two mothers of people with cerebral palsy; and one support worker	To determine whether needs of people with developmental disability were met during visits to emergency departments
Cumella	2004	UK	*Qualitative*: Consensus development: plenary and small group problem-solving methods	80 people, 40 participants each at two purposeful conferences. Participants were people with a learning disability; their supporters, family, professionals and managers	To describe the problems faced by people with a learning disability when in a general hospital, and to attain consensus on possible solutions for these problems
Hannon	2004	UK	*Qualitative*: Process evaluation using semi-structured interviews and focus groups	20 participants: four with a learning disability; five family members/carers; six hospital staff; five learning disability nurses	To identify key factors influencing the health care process and to evaluate the impact of a pre-admission assessment tool
Brown	2006	UK	*Qualitative*: Facilitated focus group at a conference event	112 delegates of a conference event. Primarily from health services (including nurses, managers, AHPs, doctors, midwives) but also from the independent sector (including social services, higher education, carers and a service user)	To identify a new research agenda focusing on improving the health care of people with learning difficulties in General Hospitals
Sowney	2006, 2007	UK	*Qualitative*: Focus groups	27 accident and emergency nurses	To explore the experiences of nurses in accident and emergency units caring for people with intellectual difficulties
Gibbs	2008	UK	*Qualitative*: Focus groups	25 participants: 11 adults with intellectual disabilities; nine parents and five paid carers	To describe the experiences of adults with intellectual difficulties and their carers in general hospitals
Webber	2010	Australia	*Qualitative*: In-depth longitudinal interviews	Interviews with a range of individuals focused on 17 group home residents with intellectual difficulties from 13 group homes. In total, 55 participants were interviewed (17 family members; 16 house supervisors; 11 accommodation programme mangers; 11 staff in aged care facilities)	To explore the hospitalisation experiences of older adults with intellectual disabilities

Table 5 Health, safety and welfare experiences identified in articles

	Care provision	Communication	Staff attitudes	Staff knowledge	Supporters & carers	Physical environment
Iacono	√	√	√	√	√	
Cumella	√	√	√	√	√	√
Hannon	–	√	√	√	√	√
Brown	√	√	–	–	–	√
Sowney 2006	–	–	√	√	√	–
Sowney 2007	√	√	–	√	–	√
Gibbs	√	√	√	√	√	√
Webber	√	√	√	√	√	–

Table 6 Findings of review mapped to the review questions

Influences that promote or compromise health, safety and welfare	Strategies to promote health, safety and welfare	Implications for research, policy and practice
Care provision		
Degree to which personal and healthcare needs are met	Availability of appropriate equipment and aids	Fiscal investment in such resources
	Use of relevant assessment tools	Provision of education and training
Communication		
Ability to communicate own needs	Availability of resources such as videos, accessible booklets, augmentative and alternative communication and pictures/symbols	Fiscal investment in such resources
Ability to be understood	Use of communication passports	Provision of education and training
Staff attitudes		
Extent to which care is provided in non-discriminatory, non-stigmatising way	Under-graduate curricula that bring students into direct contact with people with learning disabilities	Provision of education and training in a range of learning disability contexts
Staff knowledge		
Degree of knowledge regarding learning disabilities among nurses and other healthcare professionals	Under-graduate curricula that bring students into direct contact with people with learning disabilities and learning disability services	Provision of education and training in a range of learning disability contexts
	Provision of learning disability liaison services	Fiscal investment in learning disability services
Supporters and carers		
Presence of supporters and carers	Valuing carers' contribution to care and using the information they provide	Fiscal investment in resources to support carers
	Supporting carers and providing them with information and respite	Provision of education and training
Physical environment		
Extent to which the hospital environment is de-alienated	Preliminary visit to hospital and preadmission assessments	Fiscal investment in creating improved physical environments
	Appropriate signage and relaxed environment	Future research into aspects of safety

study experienced problematic attitudes of staff, particularly towards patients with communication difficulties. Cumella and Martin (2004) described an awkwardness and embarrassment among staff when dealing with people with learning disabilities. However, by the way of explanation for such attitudes, Sowney and Barr (2006) reported that nurses in their study experienced fear and vulnerability. They were confused over terminology and did not know whether to use 'mental handicap' or 'learning disability'. They were also afraid of being unable to deal with potential complexities of

caring for a person with a learning disability. Ironically, they were also afraid of discrimination – being criticised for perceiving people with learning disabilities as being 'different' (Sowney & Barr 2006). Such findings illustrate that discrimination; anxiety; and fear are often underpinned by lack of knowledge and awareness of 'Others'.

This review has highlighted a tripartite relationship of anxiety among (1) patients with learning disabilities; (2) hospital staff; (3) carers. For example, Gibbs *et al.* (2008) reported that patients with learning disabilities are fearful
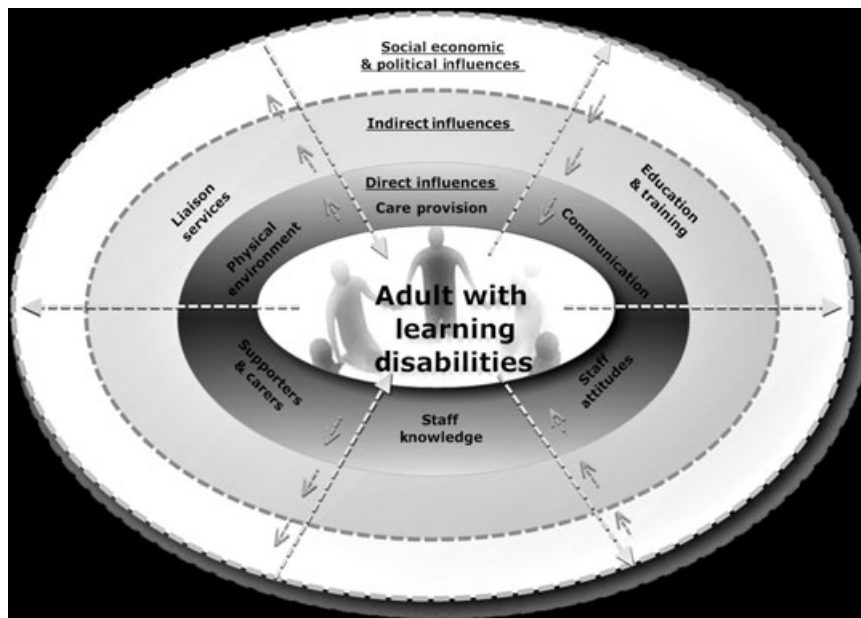
of investigations, injections, white coats and procedures. Conversely, in the same study, some hospital staff were perceived as being afraid of people with learning disabilities. Carers were also anxious about the level of care and protection provided for the person with learning disabilities (Gibbs *et al.* 2008). The problem with this pervasive context of anxiety is that people with learning disabilities pick up on it and become agitated (Gibbs *et al.* 2008), thus creating a cyclical pattern of events. However, it is important to temper these largely negative findings with the more positive experiences reported by Hannon (2004).

In terms of strategies, being exposed to a preregistration experience in a learning disability context was associated with the perceptions of more competent caring among some nurses in the study by Sowney and Barr (2006). Similarly, Iacono and Davis (2003) reported that education in undergraduate curricula that brings students into direct contact with people with learning disability can address attitudinal problems.

Staff knowledge

Staff knowledge was highlighted by most studies in the review. The study by Sowney and Barr and the two articles arising from it highlight the lack of knowledge among many nurses regarding the issue of learning disability. Most nurses had no preregistration education in learning disabilities (Sowney & Barr 2006). Lack of basic understanding reduced nurses' ability to pick up on cues, and they recognised the impact of this on their competence and confidence in 'caring'. The articles shed light on the complex relationship between learning disability and consent. Many nurses believed that people with learning disabilities cannot consent to treatment and had a misguided understanding that this was the role of carers (Sowney & Barr 2006, 2007). This is an issue that will be discussed later.

Training programmes for healthcare staff in communication are shown to be beneficial (Cumella & Martin 2004), along with mentoring by more experienced, confident practitioners (Hannon 2004). Additionally, learning disability liaison services provide a crucial role. According to Gibbs *et al.* (2008), learning disability liaison nurses can improve care for people with learning disabilities. They form an important contact point (Cumella & Martin 2004) and source of advice/support (Sowney & Barr 2006). There are different models of liaison services (Brown & MacArthur 2006), but overall, they play an important role that includes coordinating care between community and hospital and increasing staff awareness of learning disability (Sowney & Barr 2007).

Supporters and carers

Supporters and carers featured highly in this review. Most people with learning disabilities like a parent or carer with them on admission, and many chose to spend up to 24 hours per day in hospital (Iacono & Davis 2003, Hannon 2004, Gibbs *et al.* 2008). They attend to care and help with communication. Nurses value the presence of carers. They perceive that it increases their ability to assess and provide care to ill

patients with learning disabilities (Sowney & Barr 2006). However, there are tensions regarding the presence of carers and issues of overreliance. Carers often feel taken-for-granted by hospital staff and are rarely offered a break or assistance with care (Cumella & martin 2004, Gibbs *et al.* 2008).

A key strategy for supporting parents and carers is highlighted by Gibbs and colleagues. The fundamental principle is to value their significant contribution to care. Implicit within this is to use information they provide; listen to their opinions; and give practical support and respite (Gibbs *et al.* 2008). With reference to personal and healthcare needs, Iacono and Davis (2003) found a positive association between having someone stay with the person with learning disabilities and getting enough to drink. Yet again Hannon's (2004) study brought a positive slant to the review, with most carers feeling satisfied with the support they received.

Physical environment

Of the six areas identified in this review, the physical environment was the least well documented, but it still featured in five articles. In many respects, acute care settings are 'alien environments'. Hospitals are often busy, and as already discussed, this can impact negatively on adequate assessment (Sowney & Barr 2007) and means that adults with learning disabilities fear getting lost (Gibbs *et al.* 2008). There are mixed views among people with learning disabilities regarding the preference of a single room or a larger ward environment. Most parents who stay in hospital with their adult children prefer a side room to ensure privacy (Gibbs *et al.* 2008). However, as Hannon (2004) points out, although a side room may be preferred by some, they should not be given as a matter of course. It is a matter of individual choice for the person with leaning disability and their carer.

Numerous simple, yet effective strategies can promote the safety of adults with learning disabilities in hospital. Hannon (2004), Cumella and Martin (2004) and Gibbs *et al.* (2008) highlight the benefits of a preliminary visit to hospital. Indeed, preadmission assessment has been found to improve experience of admission (Hannon 2004), and carers find it helpful (Gibbs *et al.* 2008). The assessment provides the opportunity to identify individual health needs; increase staff awareness of the needs of people with learning disability; overcome problems with communication; give carers more confidence in staff (and staff more confidence in working with people with learning disability) (Hannon 2004). Conducive environments can also be created by the provision of symbols or pictures to assist those who find reading difficult (Cumella & Martin 2004, Gibbs *et al.* 2008).

Discussion

Limitations

Despite the insight provided by this review, it has some limitations. Included studies come from the UK and Australia, which potentially limits transferability of findings to other countries. Findings should thus be tentatively applied to different countries and contexts. Also, included studies are all qualitative: we found no quantitative studies that met the inclusion criteria, yet such studies may have contributed significantly to answering our research questions. We suggest this as a focus for future research. Finally, we found limited evidence regarding the physical safety of adults with learning disabilities in acute care settings. As reported, most studies are concerned with matters of patient experience and welfare. Again, this has highlighted an important area for research development. Overall, however, despite its limitations, the review has provided new insight into an under-researched area.

The six areas presented in the findings can be conceptualised as having direct influence – thus, in Fig 2, they form the closest layer to the person. However, the review has illuminated some less direct influences that in turn, influence the six areas, namely education/training and support/liaison services (as indicated by the inward direction of the arrows in Fig 2). Importantly, adults with learning disabilities are not passive recipients of care. As indicated by the arrows, they should be active agents, capable of exerting outward influence in relation to healthcare. To show the relationship between the different layers of influence, the discussion is organised with reference to Fig 2.

Direct influences on health, safety and welfare

The review findings are supportive of the wider literature; indicating that people with learning disabilities are less likely than others to obtain the healthcare they need (Disability Rights Commission 2006). In the healthcare system, they are perceived as low priority (Mencap 2007). Illness is often misdiagnosed or undiagnosed because many staff have limited knowledge of the healthcare needs of this group of people (Kent 2008). Moreover, people with learning disabilities are likely to have significantly higher mobility problems than the general population (van Schrojenstein Lantman-de Valk 2005), and falls-related injuries are common (Finlayson *et al.* 2010, Willgoss *et al.* 2010). Much of this is preventable. Understanding the unique needs of individual patients with learning disabilities can be achieved through listening to them and their carers and through

using the available resources such as communication aids and passports (Sowney *et al.* 2006).

Findings regarding communication are unsurprising, and an important, related issue is that of consent. Effective communication underpins any assessment of capacity to consent (Brittle 2004), but many nurses and other healthcare professionals do not understand the laws around capacity (Mencap 2007). Many people with learning disabilities do have capacity to consent, but inappropriate assumptions are often made regarding incapacity (National Patient Safety Agency 2004, Brown & MacArthur 2006). This has a direct influence on the person's autonomy and agency. Again, direct discussion with the patient and the use of communication aids and passports can inform a more accurate assessment of an individual person's capacity to consent. It is noteworthy that with the exception of Gibbs *et al.* (2008), all included articles were published pre- or circa-implementation of the Mental Capacity Act in England and Wales (Parliament of the United Kingdom 2005). The purpose of the Act is to protect people who lack mental capacity and allow adults to make as many decisions as they can for themselves. Time will illuminate the extent to which the Act has impacted positively on the issues of consent highlighted in this review.

Consistent with the wider literature, the review highlighted healthcare professionals' limited knowledge about learning disability (Michael 2008). Melville *et al.* (2005) identified a clear knowledge gap among healthcare practitioners, and only 8% of nurses in the study had received learning disability-related training. A recent study conducted in Belgium found that staff sometimes felt negative emotions such as depression or anger in reaction to challenging behaviour among people with learning disabilities (Lambrechts *et al.* 2009). Overall, widespread ignorance results in institutional discrimination (Mencap 2007), and people with learning disabilities are often misunderstood and misinterpreted.

As indicated in Fig 2, carers have a direct influence in supporting their relative with learning disabilities. However, carers' own needs are often inadequately met. Many healthcare professionals do not properly consult and involve them (Mencap 2007), and their opinions and assessments are frequently ignored (Michael 2008, Backer *et al.* 2009). At a physical level, there are often inappropriate facilities for families and carers in hospital, and they spend hours without being spoken to or offered a drink and spend nights sleeping in chairs, spare wheelchairs or on the floor (Mencap 2011). They can be expected to be ever present and provide physical nursing care (National Patient Safety Agency 2004, Backer *et al.* 2009). These

factors combine to cause considerable stress for carers. It is clear that carers need support. They should not be expected to be present 24 hours per day (Cumella & Martin 2004), and provision of breaks is important (Glasby 2002, Backer *et al.* 2009). At an organisational level, additional nursing staff should be provided if needed, and carers should not be used as substitutes (Royal College of Nursing 2011).

In terms of physical environment, people with learning disabilities often have difficulty adapting to new situations, and therefore, admission to hospital may be an ordeal (Glasby 2002, Brittle 2004). Backer *et al.* (2009) detailed a spectrum of factors that can lead to people with learning disabilities becoming bored, distressed, anxious or angry while in hospital. These include fear of hospital, long waiting times, being ignored and poor communication from staff. They highlighted how signage and maps may be confusing and cluttered clinical environments can hinder accessibility. However, the challenge of physical environments can be thoughtfully modified. Decluttering, appropriate signage and using colour codes are helpful. Ensuring that lighting is not too bright and that noise is minimised is also important (Royal College of Nursing 2011).

Indirect influences on health, safety and welfare

As indicated in Fig 2, the areas as discussed do not stand in isolation. They are influenced by other factors, particularly education and support. Training in learning disabilities has been found to increase confidence and reduce anxiety, fear and ignorance among staff (Glasby 2002, McMurray & Beebee 2007). Historically, however, nurses and other healthcare staff have received insufficient education and clinical experience in working with people with learning disabilities (Brown 2005, Michael 2008). Together with ignorance and fear, these factors reinforce negative attitudes towards people with learning disabilities (Michael 2008). To care for people with learning disability more effectively, nurses must overcome any prejudices and develop an understanding of learning disability (Brittle 2004). Education and training is one way to achieve this (Backer *et al.* 2009). Education is also critical in ensuring patients' healthcare needs are met, because lack of training means that healthcare staff may overlook the seriousness of symptoms (National Patient Safety Agency 2004). Improvements in treatment can be facilitated by health professional training to tackle 'diagnostic overshadowing' (Disability Rights Commission 2006); that is, failing to recognise the severity of a person's condition due to their learning disability.

Specifically, staff should be trained to communicate with people with learning disabilities (Mencap 2011).

Disability liaison nurses are crucial in supporting and educating staff (McMurray & Beebee 2007). It is several years since the National Patient Safety Agency (2004) advocated the appointment of learning disability liaison nurses in all general hospitals to ensure the safety of patients with learning disabilities. There has been subsequent support from non-governmental and healthcare organisations (Royal College of Nursing 2010, Mencap 2011). Moreover, since that time there has been mounting empirical evidence regarding the benefits of the role (Backer *et al.* 2009, MacArthur *et al.* 2010).

Central to the care of adults with learning disabilities is the patient themselves, with their own individual needs. This is reflected in Fig 2, which places the person at the core. Thus, people with learning disabilities can directly influence all six areas such as care provision, staff attitudes etcetera. It is incumbent upon nurses to ensure that this is achieved. Moreover, there is potential to influence outer layers such as education and policy. There is congruence between our views and those of others regarding the involvement of people with learning disabilities in activities such as: design and modernisation of hospital services (Brown & MacArthur 2006); research (Brown *et al.* 2010); healthcare education programmes (NHS Health Scotland 2004); and service evaluation (Campbell & Martin 2009).

Policies that support a healthcare environment in which optimal care is likely to be delivered are essential. A number of countries have augmented the chances of this happening at a legislative level. The 2010 Equality Act in the UK; Affordable Care Act in the USA; and the forthcoming Disability Act in Australia are such examples. The recently published good practice framework in Wales recommends several practices that align with the findings of this review, such as assessing for indicators of pain; taking time to provide accessible information; and developing robust communication systems (Tomlinson 2011). Again, nurses have a crucial role. Overall, as indicated by the feint markings in Fig 2, the broader context of care was not reported in our findings *per se*, but indirectly can have a significant impact on the person with learning disabilities at the centre of care.

Conclusion

Influences on the health, safety and welfare of adults with learning disabilities in acute care settings are multi-layered, and thus, improvement strategies need to be similarly multi-layered. Diagrammatic representation shows these relational elements – as direct and indirect influences – and

highlights the areas for strategy development. Situating the findings within a broader, political and socio-economic context is important because through appropriate policies and fiscal support, improvements to nursing and healthcare can be made.

Findings of this review largely mirror the recommendations of published grey literature for strengthening quality, safety and clinical practice in relation to care of adults with learning disabilities. However, as a result of the review, evidence from individual empirical studies has been synthesised to develop new perspectives. Unique contribution to nursing knowledge and practice is made by explicating the multiple, layered influences and associated strategy development, as articulated in Fig 2 and Table 6. These have potential as pedagogical tools in nursing and healthcare programmes and as leverage for political and strategic influence.

Implications for practice and/or policy

Several factors including staff attitudes and knowledge and communication and physical environment have a direct influence on the health, safety and welfare of adults with learning disabilities in acute care settings. Education and training along with nursing support/liaison services have an indirect influence, and therefore, fiscal investment in these areas is important. Crucially, through many of the mechanisms discussed, adults with learning disabilities should be supported to make decisions regarding their own care based on their unique, individual needs and preferences. Moreover, they should be involved with policy development, education, service evaluation and research. This can be achieved through inclusive approaches, for example, inviting people with learning disabilities to input into nursing curricula or engage in research as coinvestigators. This only becomes a reality, however, in the presence of genuine desire to improve the health, safety and welfare of adults with learning disabilities.

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Contributions

Study design: CB-J, MJ, SM, JR; data collection and analysis: CB-J, SM and manuscript preparation: CB-J, MJ, SM, JR.

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