

# Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study

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## Scientific summary

### Factors affecting a safer environment for patients with learning disabilities

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# Scientific summary

## Background

A number of surveys, research reports and government-commissioned inquiries have examined the health inequalities faced by people with learning disabilities in England. These have consistently highlighted poor NHS health-care provision for this population, leading to avoidable harm and premature, avoidable deaths. This has resulted in a range of recommendations and strategies for promoting better and safer health-care delivery to people with learning disabilities.

In 2008, an independent inquiry into access to health care for people with learning disabilities (Michael J. *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Aldridge Press; 2008) recommended that all NHS hospitals should:

- collect data and information necessary to allow people with learning disabilities to be identified and their pathways tracked
- have effective systems in place to deliver effective, 'reasonably adjusted' health services
- involve family and other carers as partners in the provision of treatment and care
- ensure that the views and interests of patients with learning disabilities and their carers are included in service planning and development.

These recommendations were the starting point for this study.

## Objectives

The aims of the study were to describe the cross-organisational, organisational and individual factors in NHS hospitals that promote or compromise a safe environment for patients with learning disabilities, and to develop guidance for improving practice.

The research questions were:

1. What systems and structural changes have been put in place in NHS acute hospitals to prevent adverse outcomes for patients with learning disabilities, in particular with regard to specific patient safety issues and to four selected recommendations of *Healthcare for All* (Michael 2008)?
2. How successful have these measures been in promoting safe practice, and what have been the barriers and enablers?
3. To what extent can the findings be generalised to other vulnerable patient groups?

## Methods

Six NHS hospitals in the south of England took part. The study employed mixed methodologies in three stages and lasted 21 months (2011–13).

### **Stage 1: Mapping the systems and structural changes within each hospital site (2 months)**

Strategic hospital managers at each site were asked to provide information about the policies, structures and systems that were in place in relation to the study questions ( $n = 11$ ). Telephone interviews were conducted for clarification if needed. Relevant documents were obtained and studied.

**Stage II: Examining the effectiveness of implemented measures (12 months)**

The following methods were used to assess effectiveness:

- (a) A questionnaire survey was sent via e-mail to all clinical staff in the six trusts ( $n = 990$ ).
- (b) Face-to-face semi-structured interviews were held with hospital staff including senior and strategic hospital managers, clinical nurse managers, staff nurses, health-care assistants and physicians ( $n = 68$ ).
- (c) Adults with learning disabilities who had attended the hospital during a 12-month period, and those who were members of hospital advisory boards, were interviewed using a range of accessible interview techniques ( $n = 33$ ).
- (d) Carers of patients with learning disabilities who had been patients during the 12-month period completed a questionnaire survey ( $n = 88$ ) and took part in semi-structured face-to-face or telephone interviews ( $n = 37$ ).
- (e) Participant observation of patients who were inpatients during the 12-month period ( $n = 8$ ) was carried out, including interviews with the patient (if possible), hospital staff and a carer.
- (f) Data were collected on numbers of patients with learning disabilities within the 12-month period.
- (g) Incident reports involving patients with learning disabilities within the 12-month period were monitored.

All data sets were analysed together in order to aid data synthesis. Analysis of qualitative data was supported by NVivo 9 software (QSR International, Southport, UK), using a common analytical framework that was adjusted throughout the study. Quantitative survey data were analysed using descriptive statistics, supported by Statistical Product and Service Solutions (SPSS) software version 19.0 (SPSS Inc., Chicago, IL, USA).

There was active involvement of people with learning disabilities and carers at all stages, including the design and analysis stages. Coresearchers with learning disabilities conducted interviews with people with learning disabilities.

**Stage III: Assessing generalisability to other vulnerable patient groups (2 months)**

Expert panel discussions were held with senior managers and senior clinicians ( $n = 42$ ) at four sites to discuss the generalisability of the emerging study findings to other vulnerable patient groups, in particular patients with dementia and patients with mental health problems.

**Results**

There were examples of good practice and a willingness to improve care for patients with learning disabilities across all six participating NHS hospitals, with a number of strategies being implemented. However, such good practice remained patchy.

The most common safety issues were delays and omissions of care, in particular delays and omissions of basic nursing care (for example, unmet nutrition needs) and delays and omissions of medical treatment (for example, treatment not given because of perceived inability to cope with or consent to treatment or because of staff assumptions about the patient's quality of life).

The strategies put in place by the hospitals' management included the implementation of the learning disability liaison nurse (LDLN) role, carer policies, patient-held health records and staff training, and the inclusion of people with learning disabilities and carers on advisory bodies. These appeared to have some positive effect. Across study sites, carers described some wards and staff as excellent. However, most carers could also point to wards and staff where the opposite was true. It seems, therefore, that policies and strategies do not reliably translate to better practice in the clinical areas.

## Barriers

The study identified a number of major barriers to better and safer hospital care. The most significant of these were as follows.

### Invisibility of patients with learning disabilities

Most people with learning disabilities are unknown to any health and social care services, and there is a lack of effective systems for communicating information about known learning disability between primary and secondary health-care services. General practitioners (GPs) did not routinely pass on information about learning disability, leaving hospitals unable to identify this population at the point of referral. These are significant cross-organisational barriers. Organisational barriers include a lack of effective systems for flagging learning disability and a considerable lack of staff expertise and staff willingness to identify and flag learning disabilities, encompassing not just junior staff but also the most senior managers. Many staff reported a reluctance to 'label' people.

### Lack of staff understanding

There was a widespread and persistent lack of understanding across all staff groups and all levels of seniority of the ways in which the support needs of people with learning disabilities might differ from those of the general population. Staff lacked understanding of the fact that delays or omissions of care and treatment are a particular safety risk for people with learning disabilities, and of the reasonable adjustments that may be needed to ensure that they do not happen. Staff also lacked understanding and confidence in applying the Mental Capacity Act (Great Britain. *Mental Capacity Act 2005. Chapter 9*. London: The Stationery Office; 2005) correctly to patients with learning disabilities. There were indications from all stakeholders that staff apprehension about caring for a patient with learning disabilities can lead to omissions of care.

### Lack of consistent and effective carer involvement

Staff did not always understand the essential role of carers and the importance of including carer expertise. Although there was some excellent practice whereby carers were supported and their expertise was sought and utilised by staff, many of the examples of compromised patient care involved carers who were not listened to. Carers were appreciated for the help they could give with patient care, communication and patient reassurance, but their crucial knowledge of the patient was often disregarded. Patients were put at further risk by staff making assumptions about the extent to which care would be given by carers; at worst, there were examples of hospital staff failing to provide basic care.

### Lack of clear lines of responsibility and accountability

Those with specific responsibility for the safe and reasonably adjusted health care of people with learning disabilities within the hospital, and with responsibility for co-ordinating their care, varied across study sites and included the LDLNs, the trust's clinical lead for safeguarding vulnerable adults and hospital matrons. However, while this was beneficial for some individual patients with learning disabilities, the patient population as a whole was not reliably referred to them, partly due to a lack of effective flagging systems. Although LDLNs were often effective in co-ordinating care for patients with learning disabilities, there was insufficient cover for LDLN absence. Furthermore, lines of accountability and responsibility for the care of patients with learning disabilities within the organisation were not clear. At ward or clinic level, there was no clear allocation of responsibility and accountability for ensuring that each patient with learning disabilities had his or her care and treatment needs met, and there was a lack of continuity of care. This led to good practice being dependent on individual staff members' attitudes and understanding, and the standard of care was therefore haphazard throughout the organisation.

## Enablers

The key enablers for translation of policies into practice at the point of patient contact were the LDLN and the ward manager.

### Learning disability liaison nurse

The LDLN role was pivotal in a number of areas. Hospitals with a LDLN were best able to identify patients with learning disabilities within their service. LDLNs identified individual needs for reasonable adjustments to services and were able to ensure their implementation. On-site LDLNs were better than community-based LDLNs at raising staff awareness, gaining staff trust and increasing the numbers of patients with learning disabilities identified within the hospital. However, in order for this enabling role to be effective, it had to be supported at senior management level, post-holders needed to have sufficient seniority and authority to change patient care pathways, and there needed to be sufficient cover.

### The ward manager

Wards that received the highest praise from carers and LDLNs, with reports of consistently positive staff attitudes and consistent provision of reasonable adjustments, were those in which the ward manager ran 'a tight ship'. Frontline staff were key to delivering good health care; ward managers were critical in ensuring that this happened.

### Generalisability to other vulnerable patient groups

Issues around flagging vulnerabilities and identifying and implementing the reasonable adjustments required are likely to be echoed in other vulnerable patient groups. However, the challenges around carers of patients with learning disabilities were unique, in particular identifying the need for the involvement of long-term family carers with high levels of expertise as well as the involvement of paid carers. The complexity of the needs of patients with learning disabilities and the lack of staff exposure to this group of patients makes the need for specific learning disability expertise within hospitals, for example through an LDLN service, particularly acute.

## Conclusions and implications

There is sufficient evidence to suggest that the vulnerabilities of people with learning disabilities can, and do, lead to compromised patient safety in NHS hospitals. The evidence further suggests that:

- Without nationally integrated systems for sharing information about learning disabilities across NHS services, systems that enable GPs to identify patients with learning disabilities and pass on this information to NHS hospitals, and effective flagging systems at the point of referral or entry into hospital care, many patients with learning disabilities are likely to remain unidentified within NHS hospitals.
- A clear allocation of accountability and responsibility for the co-ordination of the often complex health-care and support needs of patients with learning disabilities may reduce the patient safety risks for this group. There is a need to clarify where in the organisation the lines of accountability and responsibility lie, as well as the expertise. The evidence further suggests that allocating day-to-day accountability for the care of patients with learning disabilities to ward/clinic managers may address the current inconsistencies in providing reasonably adjusted health care.
- There is a need for adequate access to learning disability expertise within NHS acute hospitals. The establishment of LDLN roles across NHS hospitals may go some way in addressing issues of compromised safety for patients with learning disabilities, provided that these staff carry sufficient seniority and authority with clear lines of accountability and strong management support.
- The failure to involve and include carer expertise, as well as the lack of clarity about carer roles and the extent of carer involvement for an individual patient, may be addressed by the implementation of 'protocols for shared care', where the presence of carers is assessed for all patients with learning disabilities and the extent and nature of carer involvement is clarified and agreed with the carer(s) in each individual case.

- Staff do not currently receive adequate training to raise understanding and awareness of the specific vulnerabilities and needs of patients with learning disabilities, and lack adequate training in the Mental Capacity Act, both pre and post registration. Involving people with learning disabilities and carers in staff training can be particularly effective.

## Recommendations for research

Since the publication of *Healthcare for All* (Michael 2008), there has been mounting and convincing evidence that NHS acute hospitals are failing to meet the health-care needs of people with learning disabilities; this study has provided further insights into the problem. It is now time to begin to find solutions. Therefore, the following research is recommended.

1. Establishing which reasonable adjustments are needed most frequently within the hospital care pathways of people with learning disabilities, and the knowledge, systems and structures that are needed within the hospital to ensure that these reasonable adjustments are routinely made. There is also a need to assess the cost implications of reasonable adjustments, and how this can be translated into the Payment by Results system.
2. Establishing who is best placed within NHS acute hospitals to take on overall responsibility and accountability for the care pathways of people with learning disabilities and which structures are needed to support this. The structures, support and training needed by ward managers should also be established to enable them to carry day-to-day responsibility for the care of patients with learning disabilities.
3. Investigating practical and effective ways of flagging patients with learning disabilities across NHS services and within NHS hospitals, including an assessment of the barriers within primary care to sharing information about learning disabilities consistently with NHS hospitals. The views of people with learning disabilities and their carers about flagging learning disability on NHS records should be explored.
4. Investigating, implementing and evaluating protocols where the possible need for family or paid carer involvement is identified for all patients, and where the specific contributions of individual carers are clarified, agreed, monitored and recorded.
5. Investigating and evaluating the different LDLN service models that are available across the UK, in particular in relation to their authority and lines of accountability, and to the cost-benefit implications. This should include a comparison between hospitals with and without an LDLN.
6. Investigating effective ways of identifying patients with dementia and with mental health problems within the health-care system [similar to research recommendation (3)], and investigating the particular types of reasonable adjustments needed for these patients, together with their cost implications [similar to research recommendation (1)].

## Study registration

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