The invisibility of patients with learning disabilities in NHS hospitals

Dr Irene Tuffrey-Wijne
Associate Professor in Nursing
St George’s University of London and Kingston University

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Department of Health Disclaimer
The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.
“Treat me right”
2004

“Death by indifference”
2007

“74 deaths and counting”
2012
“Chief among the obstacles to delivering and evaluating the effectiveness of health services for people with learning disabilities is a lack of information about them...

It is difficult for services to prepare properly or make the necessary ‘reasonable adjustments’ if patients’ communication and other needs are unknown.”

Independent inquiry into access to healthcare
2008
Recommendations:

1. **Identify** people with learning disabilities
2. **Involve** family and other carers
3. **Represent** the views of people with learning disabilities and their carers on Trust boards
4. **Provide** “reasonably adjusted” health services
Providing reasonably adjusted health services

A legal duty

‘Where a provider of services has a practice, policy or procedure which makes it impossible or unreasonably difficult for disabled persons to make use of a service which he provides, or is prepared to provide, to other members of the public, it is his duty to take such steps as it is reasonable, in all the circumstances of the case, for him to have to take in order for him to change that practice, policy or procedures so that it no longer has that effect.’

(Disability Discrimination Act 1995, Part III section 21)
FOR A FAIR SELECTION EVERYBODY HAS TO TAKE THE SAME EXAM: PLEASE CLIMB THAT TREE
What kind of reasonable adjustments are needed?

Physical or sensory impairments:
- Ramps and lifts
- Audible and tactile signage

Impairments of memory and understanding:
*Anticipation needed that patients may have difficulties with*
- Reading letters; keeping appointments
- Understanding administrative procedures
- Understanding the purpose of care procedures or health checks
- Coping with intrusive or painful procedures that they don’t understand
How can reasonable adjustments be provided?

1. Changing the way things are done
2. Altering physical obstacles or designs
3. Providing extra aids and services
Changing the way things are done

- Staff training
- Arranging multiple procedures under 1 anaesthetic
- First appointment
- Treating patient in car park
- Ensuring patient sees same consultant
- Limit ward changes
- No visiting times for carers

Providing extra aids or services

- Learning Disability Liaison Nurse
- Bleep for patient/carer during OPA
- Food/drink/bed for carers
- Pre-treatment hospital visit
- Side room/quiet waiting area
- ‘Hospital Passports’
- Extra staff (1 to 1 support)

Altering physical obstacles or designs

- Disabled toilet
Some facts and figures about learning disability

- Estimated 900,000 people with LD in England (2% of general population)
- Only 21% of adults with learning disabilities are known to LD services (Emerson et al 2012)
- LD is always relevant when caring for someone in hospital
Figure 1. Prevalence of moderate or more severe learning difficulties in schools and learning disabilities in adults known to adult social care services or GPs.
Aims and objectives

To describe the **factors that promote or compromise a safe environment**

Cross-organisational?  
Organisational?  
Staff/teams?  
Patients/carers?

To develop **guidance for successful measures to promote a safe environment**
Research questions

1. What systems and structural changes have been put in place with regard to specific safety issues, and to the recommendations?
   - Identifying and tracking
   - Reasonable adjustments
   - Involving carers
   - Including patient/carer views
   - Avoidable deterioration, misdiagnosis, medication errors

2. How successful have these measures been?
   - ENABLERS & BARRIERS:
     - Cross-organisational
     - Organisational
     - Individual
   - GOOD PRACTICE EXAMPLES

3. To what extent can the findings be generalised to other vulnerable groups?
Who took part?

Six NHS hospitals:

Mixture of:

- Rural-urban
- Size
- Specialist LDLN roles within hospital
Project overview

Stage 1
- 2 months (Aug-Sept 2011)
- Provide baseline of systems and structural changes that have been put in place (including systems for identifying patients with LD)

Stage 2
- 12 months (Oct 2011-Sep 2012)
- Examine the effectiveness of measures identified in stage 1

Stage 3
- 2 months (Oct-Nov 2012)
- Synthesis of findings with other vulnerable groups
What have we done?

Interviews:
• Senior managers
• Ward managers
• Ward nurses
• Physicians
• LDLNs
• People with LD ~ 33
• Families/Carers ~ 34

Questionnaires:
• All clinical staff (email) ~ 1,018
• Main carers of patients with LD ~ 96

Observation:
• Selected ‘Tracer Patients’ ~ 8

Monitoring
• Numbers of patients with LD
• Incidents
• (Complaints)
The researchers

Lucy Goulding
Research Assistant

Irene Tuffrey-Wijne
Principal Investigator

Gary Butler
Co-Researcher

Niki Giatras
Day to Day Manager

Paul Adeline
Co-Researcher

Liz Abraham
Research Assistant
The Research Advisory Board

Chair: Sir Leonard Fenwick (Chief Executive, Newcastle upon Tyne NHS Foundation Trust)
Identifying
How does the hospital recognise that the patient has LD?

Flagging
Does the hospital have a system for formal notification that the patient has LD?

Tracking
Is the hospital able to monitor the hospital pathways of patients with LD?
Identifying patients with learning disabilities in Acute Trusts

A pre-requisite for the implementation of reasonable adjustments

We are not informed that patients have learning disabilities... When the patient arrives, it is immediately clearly completely inadequate for such a patient to be able to cope with the scan requested and therefore has to be abandoned...

Where it to be made known to the imaging staff that the patient had learning disabilities, allowances could have been made before the time of the appointment to cater for them.

Radiographer
How did the Trusts identify patients with learning disabilities?

None of the Trusts could give comprehensive numbers of patients with learning disabilities using their service.

- Electronic flagging system (several Trusts were developing these)
- LDLN keeping track of patients with learning disabilities
- Daily ward-checks by safeguarding lead
- “Hospital passports”
“If a patient in your care has learning disabilities, are you routinely informed of this?” *Staff questionnaire (n=783)*
“How do you find out that a patient in your care has learning disabilities?” *Staff questionnaire* (*n*=987)

- I don’t usually notice or find out that a patient has learning disabilities
- Not applicable: I have never had a patient with learning disabilities
- There is a flag or symbol on the patient board
- They are flagged on a computerised patient record system
- They have a special set of notes with them that indicates this (e.g. ‘hospital passport’)
- I notice that the patient has learning disabilities whilst caring for them
- From a medical referral letter
- The patient or the patient’s carer tells me
- There is something recorded in/on their notes
- I am alerted by my colleagues (for example, during the handover)

**Percentage (%) of clinical staff indicating 'yes' to each method**
Barriers to identifying patients with learning disabilities

- Lack of integrated systems with Primary/Social care
- Lack of effective systems within the hospitals
- The use of formal systems by staff is haphazard
Patient and carer views

I think it should be on a computer system. Or maybe a note on her notes. I understand that some people might not want to be labelled in that way, but if there is some sort of note on her system, that could lead staff to having a quiet word with the family to find out more. I don’t think anyone would mind that.

Family carer

I think staff should be made aware of it so that they know and then they know how to deal with it.

Person with learning disabilities
Barriers to identifying patients with learning disabilities

Staff: attitudes, knowledge and confidence

• Lack of staff knowledge about learning disability (they cannot safely identify learning disability themselves)

• Lack of staff understanding of the need to identify this group

I don’t see how it would affect their nursing – how we give them their care. It wouldn’t make any difference if they’ve got a learning disability or not.

Staff Nurse
Patient safety incidents highlighted in the interviews, questionnaires and observations

- Inadequate provision of basic nursing care
- Misdiagnosis
- Delayed investigations and treatment
- Non-treatment decisions and DNACPR orders
Facilitating factors needed to ensure reasonable adjustments are made

- Hospital structures, systems and policies
- Funding / resource allocation
- Management support
- Staff understanding

What do you think makes the staff so good on that ward?

I put it down to the ward manager. It affects the total attitude of all the staff.  
 Paid Carer

Equal treatment does not mean the same treatment
It's fair... everyone gets an equal amount
Developments since our study

CIPOLD recommendation: *Heslop et al 2013*

There should be ‘clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems’.

New CQC questions for acute hospitals (2014)

1. Do you have anyone with a LD in hospital at present?
2. What reasonable adjustments do you make for people with LD?
3. Do you have a specialist nurse for LD?
4. Do you audit the care given to patients with LD?
I.Tuffrey-Wijne@sgul.kingston.ac.uk

FULL REPORT: (free download)
Tuffrey-Wijne et al. 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
Health Services and Delivery Research 2013; Vol 1 Issue 13
http://www.journalslibrary.nihr.ac.uk/hsdr/volume-1/issue-13#abstract

OPEN ACCESS PAPERS
Tuffrey-Wijne et al. The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study
BMC Health Services Research 2014; Vol 14:432
http://www.biomedcentral.com/1472-6963/14/432

Tuffrey-Wijne et al. The barriers and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed-methods study. BMJ Open 2014;4:e004606
http://bmjopen.bmj.com/content/4/4/e004606.full.pdf

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