

Characterising the experiences of men and women with learning disabilities (LD) following inpatient admission to general hospital

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Acknowledgement

We thank our participants: Patients with Learning Disability, Families, paid Support Workers and Hospital Staff.

This is a summary of independent research funded and supported by the NIHR. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care

Context/background

Concerns about poor care and premature or avoidable deaths

2007

2008

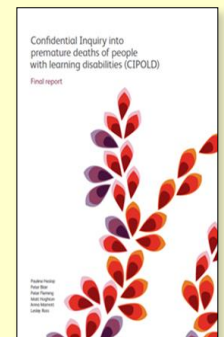
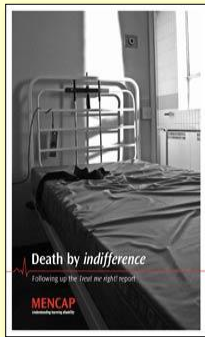
2009

2010

2011

2012

2013



Efforts to provide equitable healthcare for people with LD followed and acute hospitals have adopted various initiatives including:

Hospital passports / Purple folders



Easy read information



Learning disability awareness training



Duty to make "reasonable adjustments"



Flags to identify patients with learning disabilities



Learning disability liaison nurses



The Hospital Experiences of Adults with Learning Disabilities (HEALeD)

Work package 1 - Analysis of routinely collected data to benchmark hospital use and outcomes for patients with a learning disability against a sample of patients without LD. Two acute hospitals over two year period

Work package 2 - Hospital records used to map the inpatient stay and to assess whether LD was recognised and whether there was evidence of reasonable adjustments being made

Work package 3

Interviews: Patients with Learning Disability, Family carers, paid Support Workers

Work Package I – Analysis of Secondary Data

- A total of 999 LD patient records were analysed for a 2 year period (2012-13 & 203-14). Across 2 acute hospitals.
- Compared with a patient group without LD - cross matched for age, gender and primary diagnosis
- Some initial findings:
 - Patients with LD when compared to the general population had significantly longer stays
 - Patients with LD, had fewer additional admissions.
 - Patients with LD had a greater number of co-morbid conditions: Over half the patients with LD had 5 or more co-morbid conditions

Work Package 2 – Mapping Patient Journeys

- A total of 30 health records examined: 15 at each hospital
 - Limited information in patient records about needs relating to the person’s learning disability
 - **Difficult to separate reasonable adjustments from “good practice”**
 - More than a third of patients were recorded as being non verbal
 - More than half of patients were recorded as requiring help with eating and drinking

Work package 3 – Multi-Perspective In-Depth Interviews Exploring Patient Experiences

- To explore areas of agreement and/or disagreement between patients, paid support workers and family carers perspectives on acute hospital care
 - Semi-structured in depth interviews
 - Each interview was recorded and transcribed
 - Thematic analysis
 - 9 patients with learning disability
 - 17 family carers
 - 8 support workers

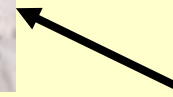
Findings from Interviews

Family Carers



Patients with a Learning Disability

Paid Support Staff



What did patients with LD say?

Struggled to critically assess their care and treatment

Likes:

- Visitors coming to see them in hospital
- Staff spending 'social' time with them – chatting and laughing
- Having someone who knows them there with them
- Some liked the food

Dislikes:

- Needles
- Noisy environment
- Waiting for things to happen
- Time dragging
- Staying in for longer than promised
- Professionals explaining things in a way that is difficult to understand/follow

What do family carers say?

Family carers said their role in hospital was VITAL to ensuring the safety and well being of their child with LD

- **Weaknesses in hospital environment** – *lack of resources, busy, overstretched clinical staff, not enough LD expertise*
- **Concerns about disability related needs of the patient** – *understanding them, needing help, needing time, severity of LD, recognising their disability or vulnerability*
- **Clinical staff not always recognising the family carer as holders of important information** – *feeling valued when consulted*
- **Emotionally committed to their role as guardian of their child's interests**
- **Expect things to go wrong** - *from past experiences*
- **Having to repeat information** - *perception of not being listened to*
- **Trusting staff** – *assess their ability to meet and understand patient's needs*

Quotes from family carers

'The thing is, there is always such a change over of staff, you just tell one member of staff something and they are absolutely amazing and the next time you go in, there's somebody completely different, and you have to explain it all again, and again and again'.....'very frustrated actually'

'I mean at the end of the day, I'm the one that knows her really, even though she's been in a home, better than anybody.they're much more aware of this now than they used to be and they do take note of what you say.....'

What did paid support workers say?

Experiences shaped by the requirement to answer the question “why are you here?”

- Support workers see themselves as skilled individuals who play an important part in the care and treatment of the person with LD in hospital
 - Allude to weaknesses in hospital setting that doesn't condemn but creates space for the support worker: Lack of experience of LD; lack of knowledge of the patient with LD
 - Carry out observable tasks on the ward: Personal care; provide emotional support; provide information to clinicians
- However they may have little or no authority in hospital setting and hospital staff may not recognise or understand their role

Implications for practice

- Training needs to include an insight into how family carers view their role and an understanding of the emotional investment they make.
- Dialogue between paid support workers and hospital staff : clarifying roles and responsibilities is key to safe, effective care.
- Wider discussion around how to identify reasonable adjustments in an in patient acute hospital setting
- Understanding the importance for patients with LD of “social time” and making a connection in fostering a positive experience
- Greater recognition of health complexities associated with patients with LD

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