Reasonable adjustments for people with learning disabilities in acute hospitals: from rare to routine?

Faculty of Psychiatry of Intellectual Disability Annual Conference, 2015
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Today

- What are reasonable adjustments?
- What do we know about reasonable adjustments in acute hospitals?
- Who is checking that reasonable adjustments are being done?
- Some questions and dilemmas
What are reasonable adjustments?

- People with learning disabilities (along with other disabled people) have a legal entitlement to have equal access to public services, including NHS services (the Disability Equality Duty)
What are reasonable adjustments?

- In law, all public sector services have a legal duty to make ‘reasonable adjustments’ to make their services as accessible and effective for people with disabilities as they would be for people without disabilities.
What are reasonable adjustments?

• Reasonable adjustments include removing physical barriers to access, but also include making alterations to policies, procedures, staff training and services to ensure that they work equally well for people with learning disabilities.
What are reasonable adjustments?

• This legal duty for health services is ‘anticipatory’.
• This means health services have to consider in advance what adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities try to use health services to put reasonable adjustments into place.
Reasonable adjustments and acute hospital care

• Strong evidence that hospitals are not meeting the health needs of people with learning disabilities:
  – Death by indifference; 74 Lives And Counting (Mencap)
  – Independent inquiry (Jonathan Michael)
  – Confidential Inquiry (University of Bristol)
What do we know about reasonable adjustments?

- Tuffrey-Wijne and colleagues: major study on safety of people with learning disabilities in hospitals (Dec 2013)

- Main findings:
  - Examples of good practice in the treatment of people with learning disabilities not consistently replicated hospital-wide
  - Most common safety issues delays and omissions of treatment and basic care
What do we know?
Main barriers...

• Invisibility of patients with learning disabilities within hospitals:
  – lack of effective flagging systems
  – lack of staff knowledge and willingness to flag this group

• Poor staff understanding of:
  – specific requirements of people with learning disabilities
  – reasonable adjustments to services people may need
  – Mental Capacity Act
What do we know?
Main barriers...

- Lack of consistent and effective carer involvement
- Misunderstanding by staff of carer role
- Lack of clear lines of responsibility/accountability for the care of each person with learning disabilities
What do we know?
Main enablers of good care...

• Learning disability liaison nurses, if...
  – Role properly supported by senior management with sufficient authority to change practice
  – Ward managers facilitate positive ward culture and ensure consistent implementation of reasonable adjustments

• [Link](http://ushamp-build.squiz.co.uk/jl/hsdhri/issue-13)
Are reasonable adjustments everywhere?

- IHaL 2010 survey of 119 NHS Trusts in England – some examples of good practice, but very patchy
Are reasonable adjustments everywhere?

• Most NHS Trusts said that they:
  – Provided easy read information for people with learning disabilities and carers
  – Trained staff to work with people with learning disabilities
  – Made sure that staff understood the Mental Capacity Act
  – Had made use of an Independent Mental Capacity Advocate with a person with learning disabilities

• Convincing evidence not always provided, fewer Trusts reported changes to routine practices/systems
Are reasonable adjustments everywhere? Liaison nurses?

- LD SAF 2014: Learning disability liaison function or equivalent in acute services
  - Green: LD liaison + data, monitoring & assurance
  - Amber: LD liaison: data, monitoring, assurance?
  - Red: No LD liaison
Are reasonable adjustments everywhere? Flagging?

- LD SAF 2014: Percentage of hospital inpatient spells that are people with learning disabilities

![Bar chart showing percentages of inpatient spells involving patients with LD across different regions.]

Figure 34: Range of the reported percentages of general hospital inpatient spells where the patient was identified as having a learning disability.
Are reasonable adjustments everywhere? Flagging?

- LD SAF 2014: Percentage of hospital A&E admissions that are people with learning disabilities

Figure 36: range of the reported percentages of accident and emergency department (A&E) attendances where the patient was identified as having a learning disability.
Are reasonable adjustments everywhere? Flagging?

- LD SAF 2014: Rates of repeat hospital A&E admissions per 1,000 people with learning disabilities
Who’s checking? Monitor?

- All NHS Foundation Trusts self-certify to Monitor if they have met 6 criteria for meeting the health needs of people with learning disabilities (Monitor Risk Assessment Framework):
  - Self-certification every 3 months
  - Only have to provide rating, not evidence underpinning it
  - Have to meet all 6 criteria to rate as compliant
Who’s checking? Monitor?

- Does the Trust have a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?

- Does the Trust provide readily available and comprehensive information to patients with learning disabilities about the following criteria:
  - treatment options;
  - complaints procedures, and;
  - appointments?

- Does the Trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities?
Who’s checking? Monitor?

- Does the Trust have protocols in place to routinely include training on providing health care to patients with learning disabilities for all staff?
- Does the Trust have protocols in place to encourage representation of people with learning disabilities and their family carers?
- Does the Trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports?
Who’s checking? Monitor?

- In January-March 2014, every NHS foundation trust reported to Monitor that they were compliant with all six criteria

(DH answer to written parliamentary question by Tom Clarke MP, 7 Jan 2015)
Who’s checking? Commissioners?

  - Green: Commissioners review Monitor returns and underpinning evidence
  - Amber: Commissioners review Monitor returns
  - Red: Commissioners don’t review Monitor returns
Who’s checking? CQC?

- CQC piloting 4 questions in hospital inspections:
  - How many patients with a learning disability are currently in the hospital (which core services)?
  - Do you have a Learning Disability liaison nurse?
  - How do you ensure reasonable adjustments are made?
  - Can you show us some outcomes from the care and treatment of patients with a learning disability?
Who’s checking? CQC?

- IHaL interim analysis of reports of inspections of 63 Trusts under the new inspection regime (until end of 2014)
- Just over half the reports (54%; 34/63) made any mention of people with learning disabilities
  - For reports on acute trusts, 50% (23/46)
  - For other types of trust, 65% (11/17)
- Amount of information varied
- Wide range of positive and negative issues picked up in reports

www.improvinghealthandlives.org.uk/publications/1242/CQC_inspection_reports_of_NHS_trusts_How_do_they_address_the_needs_of_people_with_learning_disabilities_An_interim_analysis
Who’s checking? CQC?

- Alder Hey Children's NHS Foundation Trust:
- “We identified that there was no trust lead to support young people with learning disabilities. We spoke with staff that were unclear on who coordinated services for young people with learning disabilities. Recommendations: Review the learning disability service provision to ascertain roles and responsibilities of both nurses and doctors for adolescents and young people in transition.”
Who’s checking? CQC?

- Nottingham University Hospitals NHS Trust:
  - “Accident and Emergency: Staff explained how they would support people with learning disabilities or autism. They told us that they had specific plans of care in place for people who regularly attended A&E and that they could access support from a specialist learning disability team when required. This meant patients with specific needs received care that was more individualised for them.
  - We saw staff considering a person’s capacity appropriately and discussing actions that would be taken in their best interests. Staff demonstrated a good knowledge of the Mental Capacity Act 2005. This meant staff were checking that patients could use and understand information to make an informed decision.”
Some thoughts and questions

- Why are reasonable adjustments to healthcare services so patchy?
- Can we make ‘reasonably adjusted’ services ‘business as usual’?
- What helps reasonable adjustments to happen, and what stops them?
Why are reasonable adjustments to healthcare services so patchy?

- Lots of people doing good things
- But very dependent on committed people – good practice doesn’t survive good people moving on or spread easily
- Lack of money?
  - But lots of reasonable adjustments are cost-neutral or would save money
- System inertia?
  - But systems and services can make massive changes when they want/need to (integration?)
Why are reasonable adjustments to healthcare services so patchy?

• Lack of regulation?
  – Clear indicators from regulators about what to do, but what are the consequences of non-compliance?
• Ignorance / not knowing what to do?
  – Lots of good practice out there – and why doesn’t good practice survive a committed person leaving?
Why are reasonable adjustments to healthcare services so patchy?

• Discrimination?
  – Poor health in people with learning disabilities inevitable?
  – People with learning disabilities shouldn’t be in mainstream health services?
  – Clinical skills aren’t transferable to people with learning disabilities?
  – Not high priority for health professionals’ time and effort?
  – People with learning disabilities less than human?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

Dilemmas – what’s more likely to work?

• ‘Adjusting’ services to people with learning disabilities, or
• Making ‘adjusted’ services the ‘standard’, so making business as usual more accommodating to all?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

Dilemmas – what’s more likely to work?

• Better identification of people with learning disabilities and putting in reasonable adjustments, or

• Finding out what individuals need for services to work, not relying on learning disability labels and a standard set of ‘reasonable adjustments’?

• What will work for the ‘hidden majority’?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

Dilemmas – what’s more likely to work?

• From learning disability to health literacy?
  – Align to much bigger issue of ‘health literacy’ (15% or more of population)
  – Relational, not individualised understanding of health literacy
  – But again, potential to lose focus on people who really need better healthcare?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

Dilemmas – what’s more likely to work?

• Integration of health and social care?
  – More joined-up services, smooth journeys and better identification?
  – But reasonable adjustments become even more closely tied to ‘eligibility’ for specialist support?
  – Less scope to challenge bad practice in monolithic hyperservices?
What helps reasonable adjustments to happen, and what stops them?

- At the heart of the many good reasonable adjustments I’ve seen, are people who:
  - Start from a human connection with/commitment to people with learning disabilities and families
  - Bend, break, subvert, ignore, remake bureaucracies and systems so that they work for people
  - Persuade others to be human too
What helps reasonable adjustments to happen, and what stops them?

- Can we design ‘systems’ to make reasonable adjustments ‘human-proof’?
- Or do we need to grow and nurture more humanity throughout health services?
  - Training
  - Recruitment
  - Service cultures
  - Designing services
  - All with people with learning disabilities in important roles
Thank you

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