Are you well adjusted? What do we know about good acute hospital care for people with learning disabilities

Kent and Medway Learning Disability Community of Practice Event, June 2015
Chris Hatton
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Chris Hatton
Tweeting?

#ldcop15

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Today

• What are reasonable adjustments?
• Why do we need reasonable adjustments?
• What do we know about reasonable adjustments in hospitals?
• Who is checking that reasonable adjustments are being done?
• Random thoughts and questions
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.
Why do we need reasonable adjustments?

• Bad things (all of which make people ill) are more likely happen to people with learning disabilities
  • Being poor as a child
  • Bullied and abused
  • Excluded and isolated
  • Being poor and unemployed as an adult
  • Poor health care
Why do we need reasonable adjustments?

• 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

Are reasonable adjustments everywhere?

- 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?

- 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
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
- Just over half of the reports (54%; 34/63) made any mention of people with learning disabilities
  - Amount of information varied
  - Wide range of positive & negative issues picked up in reports
Random 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 anyone?)
Why are reasonable adjustments to healthcare services so patchy?

• Lack of regulation?
  – Clear indicators from regulators about what to do, but these can seemingly be ignored or finessed without consequences (maybe an improving picture?)

• 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?
  - ‘Soft’, unspoken eugenics
  - People with learning disabilities less than human
  - Poor health in people with learning disabilities inevitable
  - Not really worth health professionals’ time and effort

#JusticeforLB
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’?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

• The limitations of flagging 1: A ‘hidden majority’ of adults with learning disabilities?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

- The limitations of flagging 2: Soon to be a ‘hidden majority’ of children with learning disabilities too?
Can we make ‘reasonably adjusted’ services ‘business as usual’?

• ‘Hidden majority’ may find learning disability label toxic
  — ...and may not at most times ‘have’ learning disability
• Does a learning disability label in and of itself tell you much in terms of how to work with a person...
• But is it better than facing a complete ignoral from health services?
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.

- Bending, breaking, subverting, ignoring, remaking bureaucracies and systems so that they work for people.

- Persuading others to be human too.
What helps reasonable adjustments to happen, and what stops them?

- Health services are bureaucracies par excellence:
  - Deliberately inhuman
  - Set people up to fail
  - Doesn’t solve inequalities in power and access to services
  - Underpinned by threat of physical violence

- Can we design ‘systems’ to make reasonable adjustments ‘human-proof’?
- Or do we need to grow and nurture more humans in health services?
Thank you!
Stuff

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