Treating people with Learning Disabilities Workshop

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Workshop outline

• What is a learning disability?
• Experts by experience perspectives
• Interactive and Scenario based sessions
• National and local evidence
• Legal Frameworks
• Leadership and Service Improvement opportunities
Workshops Background

- HEKSS funded
- 5 Workshops and one end point conference
- Collaborative project
What is a learning disability?

• The Department of Health defines a Learning Disability as including the presence of:

• A significantly reduced ability to understand new or complex information, or learn new skills (impaired intelligence), with;

• A reduced ability to cope independently (impaired social functioning);

• Which started before adulthood, with a lasting effect on development.
Confusing terms

**Mental impairment**
- Used within the UK legal system

**Mental Retardation**
- Most commonly used term across 147 countries sample by WHO in 2007 76%

**Learning Difficulties**
- Used within UK educational system

**Intellectual disability**
- Learning Disability
- Mental Handicap
Coverage of Health Checks by region 2012/13

- North East: 45.4%
- North West: 54.4%
- Yorkshire & Humber: 59.9%
- East Midlands: 61.5%
- West Midlands: 41.0%
- East of England: 57.0%
- London: 45.5%
- South East Coast: 40.1%
- South Central: 44.3%
- South West: 65.0%
- England: 52.0%

www.ihal.org.uk/annualhealthchecks
Bar chart comparing admissions to EKHUFT services pwld vs general population  

(Bailey & Marsden, 2013)
Coverage of Health Checks 2013/14 (Glover & Brodigan, 2014)

<table>
<thead>
<tr>
<th>Region</th>
<th>Coverage (%)</th>
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<tbody>
<tr>
<td>Surrey And Sussex</td>
<td>10%</td>
</tr>
<tr>
<td>Bath, Gloucestershire, Swindon And Wiltshire</td>
<td>17%</td>
</tr>
<tr>
<td>Devon, Cornwall And Isles Of Scilly</td>
<td>28%</td>
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<tr>
<td>Wessex</td>
<td>31%</td>
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<tr>
<td>Kent And Medway</td>
<td>40%</td>
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<tr>
<td>North Yorkshire And Humber</td>
<td>41%</td>
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<tr>
<td>Lancashire</td>
<td>41%</td>
</tr>
<tr>
<td>Birmingham And The Black Country</td>
<td>43%</td>
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<tr>
<td>Derbyshire And Nottinghamshire</td>
<td>43%</td>
</tr>
<tr>
<td>South Yorkshire And Bassetlaw</td>
<td>43%</td>
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<tr>
<td>Shropshire And Staffordshire</td>
<td>44%</td>
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<tr>
<td>England</td>
<td>44%</td>
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<tr>
<td>Essex</td>
<td>44%</td>
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<tr>
<td>Thames Valley</td>
<td>46%</td>
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<tr>
<td>Greater Manchester</td>
<td>47%</td>
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<tr>
<td>West Yorkshire</td>
<td>48%</td>
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<tr>
<td>East Anglia</td>
<td>48%</td>
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<tr>
<td>London</td>
<td>49%</td>
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<tr>
<td>Bristol, N. Somerset, Somerset And S. Glos.</td>
<td>50%</td>
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<tr>
<td>Durham, Darlington And Tees</td>
<td>51%</td>
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<tr>
<td>Leicestershire And Lincolnshire</td>
<td>52%</td>
</tr>
<tr>
<td>Arden, Herefordshire And Worcestershire</td>
<td>52%</td>
</tr>
<tr>
<td>Merseyside</td>
<td>54%</td>
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<tr>
<td>Hertfordshire And The South Midlands</td>
<td>56%</td>
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<tr>
<td>Cumbria, Northumberland, Tyne And Wear</td>
<td>57%</td>
</tr>
<tr>
<td>Cheshire, Warrington And Wirral</td>
<td>60%</td>
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Note: The data is drawn from Glover & Brodigan's study, published in 2014.
How people with learning disabilities used EKHUFT services compared to the general population in 2014/15 (Marsden & Bailey, 2014)
Repeated Admissions to EKHUFT services 2012 - 2015  (Bailey & Marsden, 2015)
What is the MCA

• A statutory framework to ......
• empower and protect vulnerable people who may not be able to make their own decisions
• make clear who can take decisions in which situations and how they should go about this
• enable people to plan ahead for a time when they may lose capacity
Assessing lack of capacity

- Single test for assessing capacity to take a particular decision at a particular time
- Decision-specific test
- No one to be labelled ‘incapable’ as a result of a particular diagnosis
- THIS decision at THIS time for THIS individual
5 key principles

1. A person must be assumed to have capacity unless it is established that they lack capacity.

2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

4. An act done, or decision made, under this Act for or on behalf of a person must be done, or made, in their best interests.

5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way which is less restrictive of the person's rights and freedom of action.
Assessing capacity

Assessing capacity is:

• **Decision** specific, **time** specific
  - *Because capacity can be decision and/or time specific*

• Has a **2 stage** test:
  1. Does the person have an impairment of the mind or brain?
  2. If so, does that impairment mean the person is unable to make the decision at the time it needs to be made?
Assessing ability to make a decision

A person is unable to make a decision if they cannot:

1. **understand** relevant information about the decision to be made

2. **retain** that information in their mind

3. **use or weigh** that information as part of the decision-making process, or

4. **communicate** their decision by any means.
Best interests - The decision maker must:

1. **Involve** the person who lacks capacity

2. **Have** regard for past and present **wishes, feelings, values, beliefs** and especially **any written statements**

3. **Consult with and take into account others** who are involved in the care of the person, especially any legally appointed person, eg a Lasting Power of Attorney (LPA) or Independent Mental Capacity Advocate (IMCA)

4. **Not make assumptions** based solely on the person’s age, appearance, condition or behaviour

5. **Demonstrate and document** the process of decision-making
What may trigger an assessment of mental capacity?

• The way a person behaves
• Concerns raised by someone else
• Receiving a diagnosis
• Major change in care provision
Factors to be considered

• General intellectual ability
• Memory
• Attention and concentration
• Reasoning
• Information processing
• Communication (understanding and expression)
• Cultural influences
• Social context
What are Reasonable Adjustments?
### 4C Framework for Making Reasonable Adjustments

*(Giles & Marsden, 2014)*

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<thead>
<tr>
<th>Communication</th>
<th>Choice Making</th>
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<tr>
<td>Collaboration</td>
<td>Coordination</td>
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Tools for Adjustments

• Easy Health website

• Hospital/ Healthcare Passports

• Hospital Communication Book

• Books Beyond Words

• DisDAT pain assessment tool
Reasonable Adjustments: Case studies

- 2 basic case studies to work up
- No right or wrong answers
- Consider the legal and 4C’s Framework

Questions
- What are your first thoughts?
- What questions do you have?
- How could you answer those questions?
- What action would you take?
Care pathway activity

• Areas for consideration:
  – What can you learn from that experience?
  – What are the assumptions care pathways based on?

• Activity
  – Plot the pathway for the individual.
  – Plot the adjustments that could be made.
Your Care Pathways

- Plot how people come to your service
- Include the steps of your service
- Exit point from your service
- Thinking about 4C’s, are there any adjustments that could be made?
Other reference points

- Kent and Medway Learning Disability Community of Practice
  https://kentlivewell.wordpress.com/

- Social Media for Networking
  http://www.wecommunities.org/

- HEKSS Urgent Care Report
  http://www.canterbury.ac.uk/News/newsRelease.asp?newsPk=2367
What’s next?

• What adjustments could you make?

• What are the first actions to having this happen?

• Final Conference?
References

- University of Bristol (2013) Confidential Inquiry into Prematures Deaths of people with learning disabilities. Available online at http://www.bris.ac.uk/cipold/