

**Hidden in plain sight:
mental capacity and
acquired brain injury –
*paternalism or unnecessary risk
promotion?***

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Aims of the day....

- ◆ To share knowledge and experience
- ◆ To develop a greater understanding of ABI and its implications for decision-making
- ◆ To identify ABI specific difficulties that make process of assessment/intervention far more complex
- ◆ Recognise existing abilities and resources to support this

Possible outcomes

- ◆ Increased knowledge of ABI
- ◆ Increased knowledge of why ABI specifically impacts upon decision-making capacity
- ◆ Increased ability to apply this knowledge in situ, how to assess.
- ◆ Increased recognition of our inner “Dunning-Kruger”
- ◆ Greater awareness of where and when to seek support

How will we achieve this?

- ◆ Positively sharing experiences, including those that did not go so well – so please join in
- ◆ Sharing tips and pointers

But.....

- ◆ ...it is a huge topic, one that we cannot hope to cover in 45 minutes
- ◆ My personal aim is that....
- ◆ Some/all/one of you will be motivated to further learning and specialism. Families affected by ABI need knowledgeable and passionate people

Personally affected?

- ◆ It is statistically highly likely that there are individuals in this room who have personal/familial experience of ABI
- ◆ Absolutely no obligation to share, if you do, we need to respect your experience
- ◆ Hope
- ◆ Confidentiality

So, who is in the room?

- ◆ Anyone with direct experience of working in specialist ABI settings?
- ◆ Background qualification/experience?
- ◆ If you do not understand anything, stop me, you may not be alone and we should explain everything as we go along. (I will probably need to do the same to you!!)

Who has an ABI?

- ◆ 2 main groups, men aged 16 to 40 and women aged 85+
- ◆ But younger female ABI on the increase.
- ◆ Traumatic v non-traumatic, what are the causes?
- ◆ Incidence and prevalence?

(Source: www.headway.co.uk)

What is an ABI?

- ◆ The uninjured brain.....
- ◆ becomes injured.....
- ◆ Primary and secondary injuries
- ◆ Bio-markers. Why are these relevant to you?
- ◆ Severity?
- ◆ Function?

Impact of ABI on an impairment level *(WHO terminology)*

- ◆ Physical and sensory impairment.
- ◆ Cognitive
- ◆ Behaviour/mood
- ◆ Socio-communication
- ◆ Of most relevance perhaps to us today?.....
- ◆ Executive and meta-cognitive. (Insight)

So what does this actually mean?

- ◆ Idea generation, reasoning, decision-making, problem-solving, initiating, recognising and responding to feedback (in the moment), abstract thinking, planning, organising and time management are.....
- ◆ ...difficult to assess, impact more greatly upon decision-making than cognitive impairments, are harder for individuals to have insight into, are easily misunderstood as behaviour/choice. Intellectual awareness is a confounding factor.

Functional impact

- ◆ Employment
- ◆ Relationships
- ◆ Homelessness and prison. Why?
- ◆ Mental health and suicide.

Family

- ◆ What do you think?
- ◆ What does the research say?
- ◆ Ambiguous loss
- ◆ Independence or interdependence?

Family continued

- ◆ Families all function differently prior to the injury, coping styles, former roles and beliefs will impact upon outcome and post-injury functioning.
- ◆ Overly-protective? Abusive? Any examples?
- ◆ Impact of compensation. Impact on relationships?
- ◆ Usually doing the best they can in taxing circumstances without adequate support.

Impact upon family, research evidence

- ◆ Themes of context, all-pervasive nature, grief and loss, unavailability of burden, poor experience of services and positive experiences and changes too.
- ◆ Evidence that impact of injury develops over time, deterioration in functioning is commonplace.
- ◆ Evidence of benefit of “expert companion”.

How does this impact upon Capacity?

- ◆ Understanding information
- ◆ Retaining information
- ◆ Weigh up and use information
- ◆ Communicate the decision

What did the HoL say about ABI?

- ◆ Report: *Making the Abstract Real* identifies ABI specific issues picked up by their lordships

- ◆ Report available at www.head-first.org/research-and-publications or

https://www.researchgate.net/profile/Mark_Holloway4/stats

- ◆ Repeating concerns regarding lack of knowledge by assessors and failure to integrate 3rd party knowledge PLUS no recognition of “Serial poor decision makers”

What are the criticisms made?

- ◆ Lack of recognition and understanding of impact of ABI
- ◆ Taking individuals at “face value”, failure to triangulate
- ◆ Structured assessments “create” capacity, it may only exist in this setting
- ◆ Capacity is performed, not simply a stated intention
- ◆ Intellectual awareness is not insight

Examples:

- ◆ Declaration of Best Interests, removal from community
- ◆ Ending of a relationship
- ◆ Locking of food cupboards

So how to assess?

- ◆ Remove distractions, slow down, explain, provide ideas and examples?
- ◆ Or does that simply provide an opportunity, in the abstract, to demonstrate “capacity” or reasonable decision making when, without this externally created scaffolding, functioning is entirely different to verbal output?
- ◆ Triangulate, test, refer, look at real-world functioning

Take home messages

- ◆ It is really complex, that is ok, you do not have to know everything
- ◆ It is a family condition, it is not the same as other conditions
- ◆ Executive impairment and lack of insight/intellectual awareness are our greatest challenges.
- ◆ Assessing words NOT performance is a major mistake.
- ◆ How can you triangulate your evidence, where are your sources?

Take home messages 2

- ◆ There is evidence that people with an ABI are dying for a lack of intervention.
- ◆ HoL recognises that lack of intervention promotes unnecessary risk.
- ◆ There are specialists who are able to help. If this is likely to end up at the COP then the more specialist they are and the sooner the better
- ◆ Assessment over time? A snapshot more likely to be dangerously inaccurate.

Take home messages 3

- ◆ You are now likely more knowledgeable about ABI than your senior management.
- ◆ Your work practices need to adjust to take account of the reality of the injury. A snap-shot based upon verbal output of a person lacking insight is unlikely to be adequate and may place them, others and you at risk (professionally).

Further support and information

- ◆ Headway, national and local (go to a meeting)
- ◆ Child Brain Injury Trust, BIRT, OZC
- ◆ UKABIF and BISWG
- ◆ Twitter (no, really!)
- ◆ BABICM
- ◆ Head First

That's it for today

- ◆ Thank you for your time and your commitment to the lives of families affected by ABI.
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