Select Committee on the Mental Capacity Act
Headway - the brain injury association response

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Introduction

On the 16th July 2013, Headway's Chief Executive, Peter McCabe, gave evidence at a House of Lords Select Committee inquiry on the Mental Capacity Act and how it is being implemented.

Peter presented the views and opinions of Headway service users and key stakeholders with direct experience of the Mental Capacity Act (MCA/The Act)while also highlighting areas where the Act needs improving in order to acknowledge the specific challenges faced by people with brain injury..

The Select Committee's aim is to review the MCA, which was introduced in 2005, and work towards implementing any important changes that may be necessary.

This document summarises the evidence Headway presented to the Committee.

Headway - the brain injury association evidence

This section addresses some of the questions that were discussed at the Committee meeting. Further discussion is included in the *Key issues* section below.

I. The Act

At the time it was passed the Mental Capacity Act was widely viewed as progressive and welcome legislation. Has the Act lived up to these expectations? Are there benefits or problems that were not foreseen at the time the legislation was passed?

The Act was, and continues to be, generally well-received and it is recognised that it performs a vital role in safeguarding the interests of many people who lack capacity.

There is little specificity to brain injury however, and gaps in service provision and general understanding of this complex condition undermine the principles of the MCA.

Advocacy

Independent Mental Capacity Advocate (IMCA) services were initially hailed as a means of supporting people, and Headway welcomed their introduction. However, in reality these services are extremely limited and officers are very often not specialists in brain injury.

Making decisions on behalf of someone who lacks capacity

The process of applying to make decisions on behalf of someone who lacks capacity is long, expensive and complicated. While we recognise that it is vitally important that these decisions are made with every possible care, we do have concerns that the complexity of the system may deter people from seeking appropriate authorisation, particularly in less clear-cut financial and welfare situations.

Treatment decisions

The process of making important life-prolonging and/or advance medical treatment decisions is extremely complex. We have heard a number of reports from families that are fighting to get appropriate treatment for relatives, with significant further distress being caused while relatives of those with very severe brain injury are in reduced states of consciousness.

What changes, if any, would you make to the Mental Capacity Act 2005 or Code of Practice?

In our consultation with Headway service users and stakeholders with experience of the MCA, we have identified a number of changes that could make the Act more appropriate for people with a brain injury.

These include:

- Simplify guidance on best interest decisions
- Create brain injury specific IMCAs and make advocacy services available to all
- Ensure mental capacity assessments are performed by appropriately trained staff, particularly for those people with complex conditions such as brain injury
- Simplify the process of appointing deputies and ensure more regular supervision
- Provide additional training and clarification on the Act for medical professionals so they fully understand their responsibilities

II. Understanding and use of the Act

Previous witnesses have commented on differences in understanding of the Mental Capacity Act among professional groups. Does this reflect the experiences of those that you work with? Does this change for different settings, such as hospitals, types of decision or for different types of impairment or for those with fluctuating capacity?

The lack, or inconsistency, of understanding of the MCA is a major problem for implementation of the Act. Professionals at all stages of care may be required to either perform or refer patients for capacity assessments, be it for normal everyday decisions, or more complex treatment and care issues.

We feel it is essential that anyone who may reasonably have involvement in capacity issues should receive adequate training, both in the MCA and the medical condition of the person they represent.

Too many people with brain injury are being referred for inappropriate care or no treatment at all. We regularly hear reports of individuals being placed in residential units specialising in mental health issues, rather than brain injury, putting them at risk of inappropriate treatment and care decisions made on their behalf.

To summarise:

- There is a lack of consistency with capacity assessments
- There is a disparity of understanding among medical professionals

Are families, carers and individuals who may lack capacity aware of and able to access their rights under the Act, including through the role of Independent Mental Capacity Advocates and the Court of Protection?

As discussed, we do not feel that this is always the case.

Our helpline regularly receives enquiries relating to capacity issues - often from relatives of people with severe brain injury who have received no information or support to help them make decisions on behalf of a loved one.

This lack of information in the early stages can lead to big problems - these could range from treatment decisions being made that do not take into account the patient's wishes and values, to financial hardship incurred because no appropriate measures were put in place following the loss of a household wage-earner.

Headway has produced literature to try to provide this information to people. However, IMCA services remain elusive for many, and the process of applying to the Court of Protection is unduly complicated.

It is clear that the provision of IMCAs with specialist knowledge of brain injury would be of great benefit to people with a brain injury, their families and carers.

Has the role of the Independent Mental Capacity Advocates succeeded in providing a voice for those who have no-one to speak on their behalf, and an additional safeguard against abuse and exploitation? Do you have any concerns about the varying rates of referral across different local authorities?

As previously discussed, the concept of the IMCA service is a very good one. When navigating such a complex area, families, who are often going through an extremely difficult time, need good quality specialist support.

However, availability of these services is limited, which makes it very difficult for us to get accurate feedback from our service users.

Many IMCA services are run by mental health and learning disability organisations rather than brain injury specialists. We would suggest that measures be put in place to increase access to IMCA services, including commissioning of those with knowledge of brain injury.

Some service users have raised the issue of a need for independent advisors to be available in acute care settings to assist families in dealing with the complexities of the MCA at times of huge distress and anxiety. We feel the Act would be improved if it recommended or required the provision of IMCA-like services in all acute care units, and/or Citizens Advice Bureaux.

III. Assessments of Capacity and Best interests

We have heard contrasting views on how easy it is to assess capacity in practice and it has been suggested that some practitioners conflate the assessment of capacity with an assessment of best interests.

What is the experience of your client group of how capacity and best interests are assessed in practice? Are there issues particular to specific types of impairment, such as acquired brain injuries or dementia, particular settings or particular professionals that affect capacity assessment?

Brain injury is an extremely complex condition. Individual needs vary greatly, with the wide-ranging effects of the condition, psycho-social factors, and the availability of a support network leading to big differences in capacity.

People often present well to assessors in informal assessments lasting up to half and hour, but the reality is that short meetings often do not accurately reflect the individual’s day-to-day life.

Could environment skew assessments? Is it possible a person with a brain injury could perform disproportionately well in an assessment carried out in his/her own home compared to conducting the interview in a unusual setting outside of their comfort zone, such as a new rehabilitation unit? Are brain injury-related issues such as anxiety and fatigue taken into account in such situations? Are people who lack insight into the effects of their conditions adequately supported in the MCA and related capacity assessments?

Are the law and Code of Practice sufficiently clear for practitioners and informal carers to follow? Are assessments of capacity and/or best interests happening in accordance with the Act?

There is a disparity of understanding, which is discussed throughout this document.

The need for families, civil partners and carers to be consulted and involved in decisions about best interests was stressed by a number of submissions to the pre-legislative scrutiny committee.

Key issues

This section provides further detail on our feedback regarding four key issues of the MCA:

- Autonomy vs protection
- Assessment of capacity
- Gaps in understanding
- Advocacy

This is intended as more detailed evidence to support the questions presented above. As such, much of the information will overlap.

Autonomy vs Protection

This is already a key aspect of the Act and it is proving very difficult to strike the correct balance on such a delicate principle. It's a principle that is at the heart of the MCA.

At what stage does a person need protecting from their own decisions? If they are deemed to have capacity, shouldn't they be able to make their own choices, regardless if seem by some to be the 'wrong' choices?

An example we received from one solicitor is that a person may have capacity to make a decision to purchase a large, expensive household item, such as a TV. However, they may lack capacity to understand the consequences of making a number of similar decisions, which may lead to financial difficulties in future. One single decision to make a one-off purchase may be fine, but does the individual have a sufficient understanding of budgeting to know that the purchase will impact on the individual's ability to make further large purchases?

The MCA must make better provision for 'linked decisions' such as these.

It should also make specific provision for some of the often hidden effects of brain injury, such as lack of awareness and insight, impulsivity, inflexibility and obsessional behaviour. These serious effects can be extremely difficult to assess, particularly for professionals without the correct level of specialist knowledge, but yet can have a major impact on welfare.

Assessment of capacity

People with brain injury often 'present well to assessors in informal assessments lasting up to half an hour', but the reality is that short meetings often do not accurately reflect the individual's day-to-day life.

Could environment skew assessments? Is it possible a person with a brain injury could perform disproportionately well in an assessment carried out in his/her own home compared to conducting the interview in a unusual setting outside of their comfort zone, such as an office? Are brain injury-related issues such as anxiety and fatigue taken into account in such situations?

Gaps in understanding

Currently, it is often left to healthcare professionals to make decisions in the best interest of a patient lacking capacity. However there are significant gaps in knowledge among healthcare professionals when it comes to brain injury.

Too many people with brain injury are being referred for inappropriate care or no treatment at all. We know of individuals placed in residential units specialising in mental health issues, rather than brain injury. This is one reason that Headway has launched our Approved Provider scheme, to assess units against detailed criteria that ensure their expertise in brain injury.

Similarly, Headway has recently worked in partnership with the RCGP to try to assist GPs in diagnosing and referring patients affected by brain injury, again borne of the need to improve healthcare professionals’ understanding of this complex condition.

Best practice choices must be based on having all and appropriate information. The Act must take into account the fact that this is not currently the case.

Advocacy

This issue has been discussed in detail above, but ensuring that family members and carers of people who lack capacity are adequately supported is key to the successful implementation of the MCA.

Headway is calling for the MCA to be strengthened to require a minimum provision of IMCA services, with specialist training in the condition they are supporting, and available at all relevant points including critical care units.

Feedback from professionals

In compiling our evidence, we sought the views of a number of professional stakeholders, including legal professionals who are involved in capacity and best interest decisions for their clients.

The following points summarise the feedback we have received from a number of professionals on how the MCA is working, the challenges they and their clients face, and how things could be improved. These points have been selected as they echo the feedback we have received at Headway over a number of years.

- There is a general feeling that the MCA has been a success, and provides valuable support and protection to people who lack capacity. The MCA has put principles of best practice into law and helped clients to be involved in the decision making process as much as possible, while ensuring decisions made on their behalf are in their 'best interests'.

  The MCA allows common sense to be applied, which ensures it does not act as a barrier to people receiving the support they need. This is important legislation which successfully helps to preserve the basic rights and independence of people with brain injury, and offers vital support to their family and carers.

- The MCA requires that 'all practicable steps' are taken to help a person make a decision for themselves. There is a feeling that this is at odds with other aspects of the Act, which require decision makers to encourage a person to participate only 'so far as reasonably practical'. There could be more clarification on the level of involvement a person is required to have, in particular with relatively minor decisions.

- It can be difficult for professionals and family members to judge whether a person is making an 'unwise' decision, which the MCA protects their right to make, or whether they lack the capacity to make a decision. More support and clarification on these definitions would be helpful, although this area will always be difficult to get right.

- Similarly, there is some concern that the presumption of capacity can, in some cases, lead to people with a brain injury being vulnerable. This is particularly the case where large settlements are awarded and in reality they find it extremely difficult to handle large amounts of money.

- The MCA is very good at dealing with individual decisions, but there is a feeling that it could be strengthened to take into account a person's ability to understand the consequences of a series of decisions over time.

For instance, a person may have capacity to make a decision to purchase a large, expensive household item. However, they may lack capacity to understand the consequences of making a number of similar decisions, which may lead to financial difficulties in future, i.e. one single decision to make a one-off purchase may be fine, but that purchase will impact on the individual's ability to make further large purchases. This concept may not be fully understood by the individual.

We suggest a new section 3(4)(c) which incorporates "the possible consequences of the decision alongside another decision or decisions made in the past or future".

- Section 16(4)(a) of the MCA specifies that "a decision by the Court [of Protection] is to be preferred to the appointment of a deputy to make a decision". We feel deputies offer the opportunity to make decisions much more quickly with the person's best interests in mind. In reality, deputies are appointed in most property and financial affairs cases, and the Act should be amended to reflect this.

- We have concerns about reports of a reduction in Court of Protection resources that has led to a significant reduction in the supervision provided to deputies. It is vital that spot checks and inspections are made on a deputy's activities in order to protect the welfare of people who lack capacity. Similarly, regular checks provide important support to assist deputies in their role.

  We would ask that the MCA includes a requirement that inspections are made at appropriate intervals to ensure the protection of vulnerable clients – and indeed the deputies themselves.

Feedback from service users

In producing this report we gathered feedback from our members, asking them to tell us their views on the MCA.

Mrs A:

Mrs A's sister is in a minimally conscious state following a catastrophic brain injury. Her experience of the Mental Capacity Act relates to the general and life-sustaining treatment and care decisions being made about her sister by the clinical team, following her admission to hospital and later a care home.

Mrs A feels that in practice the MCA is not working due to a lack of staff training, a clash with established practice and organisational structures which make the incapacitated particularly vulnerable. She highlights the following issues:

1. There is a need for more training for staff in health and care settings - good, high-quality training with personal stories that show it matters, not online modules that people simply tick off. This is because it's not just a question of information but a need for cultural change.

2. There is a need for good information for families so they understand their role and the patients' rights.

3. Organisational changes are needed if the MCA is to work – e.g. (a) better transfer of information between clinicians and sites (as person themselves cannot be their own 'continuity of care' person, (b) advocates in hospitals for every incapacitated patient.

4. Possible changes to the MCA (e.g. to clarify that a 'best interests' decision does not always mean intervention to sustain life, or vice versa – must take account of patient's own pre-injury views and values.

5. Advanced Decisions (ADs) and promoting end-of-life planning: Although the MCA made provision for ADs, the terms are so stringent (and public information so limited) that this isn't working well. There is a need to re-visit the terms of what makes a valid and applicable AD, provide public information and support ADs in writing. Also clinicians should not treat the absence of an Advance Decision as meaning the person's expressed beliefs (as reliably documented in other ways) have no influence in relation to life-sustaining treatments.

5. More generally, the danger of under-treatment is well documented (because medics make 'quality of life' judgments against profoundly disabled people). The other side of the coin is the danger of over-treatment - based on an equal disregard for the person's own values and beliefs, and a fear of being sued. Medics made comments to me like 'no one has ever been sued for saving a life'. We need clinicians to be supported in ways that lead to neither over-treatment nor under-treatment.

My general personal impression is that staff I encountered were ignorant of their duties under the MCA - and could not believe/did not *want* to believe what those duties were when I tried to inform them.

Staff defined a 'best interests' decision as a 'clinical decision' - and just saw it as a matter of clinical judgment. From the moment of my sister's accident it was as if she belonged to them, they were not interested in what we knew about her and her wishes. I can understand this in the immediate emergency but this went on for months and months, it was a constant battle.

I think this was a combination of ignorance about the MCA, and lack of time, and business as usual. Also it was unclear who the decision maker actually was for most things, so in the absence of her ability to represent herself at the time, my sister was just an object to be processed.

The system is not well adapted for patients without capacity - they need an advocate on the spot who can collect relevant info from the family and who knows the system. Because they didn't collect and process what she would have wanted, and anyway had a fear of allowing her to die, they acted with disregard to her prior expressed wishes.

Comments from other service users

Other service users provided us with brief accounts of their experiences and perceptions of the MCA:

Mrs B:

"Luckily my hubby has just passed his mental capacity test. If not then the court of protection would have taken over. The procedure of the test lasted approximately one hour, it was actually done very well. It wasn't invasive and it’s more common sense questions. Everything was discussed properly to make my hubby understand it properly."

Mrs C:

"I think that Act might have saved my bacon. I was saved by a clause the judge handed to me because he could see how bad things had become. If it wasn't for the olive branch that the judge handed me I would have my tribunal rejected."