

"The problem is, when you are ill, people don't keep you informed...and they withhold information from you. This is not the right time to withhold information as you can't decide things like medication if you don't understand all the facts, therefore you are left with no choices" (Mental Health Service User)

Introduction

Mental capacity - the ability to make decisions - is an issue that affects everyone. We all make decisions, big and small, everyday of our lives. Most of us are able to make these decisions for ourselves, although we may seek information, advice or support for more serious or complex decisions.

However for large numbers of people (for reasons of illness, injury or disability) their mental capacity may be affected in ways that prevent them from making certain decisions about their lives (on a temporary or permanent basis) and decisions are therefore made on their behalf. These include people with serious mental health problems, people with dementia, and people with learning disabilities.

In the absence of a clear legal framework, the government developed the Mental Capacity Act (MCA); this enshrined in law good practice and introduced a number of important principles. The Mental Capacity Act came into full force on 1st October 2007 and its main principles are

The five principles

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision.
- People have the right to make what others might regard as an unwise or eccentric decision.
- Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests.
- Anything done for, or on behalf of, people without capacity should be the least restrictive of their basic rights and freedoms.

Major points of the Act you might need to know

IMCAs - Independent Mental Capacity Advocates for people who lack capacity and have no-one else with whom the decision-maker can consult, where decisions are being made about serious medical treatment or a change in the person's residential accommodation. IMCAs commenced working in England in April 2007 and in Wales in October 2007.

LPA's - The MCA allows people to make a Lasting Power of Attorney (LPA) which replaces the existing system of Enduring Powers of Attorney (EPAs). As with EPAs in making an LPA people will still be able to appoint someone to make decisions on their behalf about their property or financial affairs but for the first time, the MCA allows people to make an LPA to also cover decisions about their personal welfare and health.

Court of Protection - A new Court of Protection is created by the MCA which replaces the existing Court of Protection. The Court will deal with any cases brought under the MCA and is expected to adjudicate in particularly complex or disputed situations, including issues concerning whether or not someone has capacity to make a decision, and best interests determinations. It will be able to make declarations (e.g. about someone's capacity), make decisions on behalf of someone who lacks capacity, and appoint deputies to make decisions on behalf of someone.

New criminal offense - The MCA also creates a new criminal offense of ill-treatment or wilful neglect of a person who lacks capacity by someone caring for them and this applies to people of any age, including children. The offence came into force in both England and Wales in April 2007.

Assessing Capacity

The MCA itself does not require any specific procedure to be followed when assessing a person's mental capacity nor does it require specific individuals, such as particular professional disciplines to be involved (in contrast to mental health legislation). There are no specific forms that must be filled out and there is no 'certificate of incapacity' that is issued (unlike in Scotland where in some cases GPs must complete a certificate). This is because the MCA covers virtually all decisions great or small, and is also time and decision-specific - this is known as the 'functional test' of capacity (see box below).

The Project

For the Mental Health Foundation (incorporating the Foundation for People with Learning Disabilities (FPLD)) issues of mental capacity and the MCA are of enormous importance. The Foundation is the only organisation of its kind in the UK to work with so many of the key groups of people affected by the MCA, together with their carers and health and social care staff. The Foundation conducted a study which explored the knowledge of existing practices in services throughout

The functional test of capacity

- Does the person have an impairment of, or disturbance in, the functioning of the mind or brain (it does not matter if this is permanent or temporary)?
- If the answer is yes, does it make the person unable to make the decision? This can be found out if, after all appropriate help and support to make the decision has been given to them they cannot:
 - Understand the information relevant to that decision
 - Retain that information
 - Use or weigh up that information
 - Communicate their decision

If any of these apply the person lacks the capacity to make decision.

England and Wales. The study assessed staff knowledge of issues surrounding mental capacity, staff awareness of the Act, and training provision prior to the Act. The study also conducted in-depth consultation with service users and carers regarding their experience of mental capacity issues and their experience in services.

Specifically, the research addressed five questions:

1. How do staff and organisations define mental capacity and decide when it needs to be assessed?
2. What training and guidance is currently available to staff regarding the Act?
3. What is the experience of service users in being able to make decisions and make their choices known?
4. What is the experience of carers in enabling those they care for to make decisions and in making their choices known?
5. What is the experience of carers and service users of mental capacity assessment?

Method

We visited 16 sites across England and Wales, we talked to staff and asked them to fill in a questionnaire, and interviewed both service users and carers about decision making and mental capacity. We talked to 73 staff in total and 20 service users and 6 carers.

What Staff had to Say

Defining capacity - Staff defined mental capacity in a variety of different ways, a majority of respondents (83%) included 'an ability to make a decision' in their definition of capacity. Of these, more than half linked the ability to make decisions with some form of cognitive competence. For the most part this

was expressed as a person's ability to understand information or make an informed choice, but some looked for "logical", "reasoned", "competent", "wrong or right" or "realistic and safe" decision making as a mark of capacity.

Training - Staff indicated an overwhelming desire for more training and guidance, 59% stated they had received 'a little' and 36% stated they had not received any. What guidance was received seemed to have primarily come from a formal course (44%) with some 13% from local training. When asked if staff would like more training on the issue 59% said 'yes a lot' and 39% 'yes a little'.

Assessment of Capacity - Staff were asked to describe how they would decide that someone's capacity needs to be assessed and responses to this question were grouped into six major categories:

1. Assessments associated with the process of making decisions (e.g. an assessment of capacity might be triggered when an individual appears to have problems with one or more aspects of decision-making)
2. Assessments associated with the impact of decision-making (e.g. an assessment of capacity might be triggered by the consequences of a decision being made)
3. Situational assessments (e.g. an assessment of capacity would take place in relation to a specific decision that needed to be made)
4. Service-led assessments (e.g. an assessment of capacity might be associated with some aspect of service provision or part of a care planning process)
5. Assessments associated with individual characteristics (e.g. an assessment of capacity might be triggered by a person's long-term condition, mental health history or their previous behaviour)
6. Assessments associated with changing circumstances (e.g. an assessment of capacity might be triggered by a change in a person's ability, mental state, behaviour or their condition)

It is worth noting that the final three categories are inaccurate interpretations of when mental capacity should be assessed (if applied on their own) according to the Act. Standardising good practice is one of the major impacts of this legislation.

Comparisons across Service Sector

The staff survey results were compared between service sectors (Mental Health services, Learning Disabilities services and Older People services). There were no significant differences in how frequently assessments were carried out between sectors, however there was a significant difference in who carried out the assessments ($\chi^2 = 30.06$; $df = 10$; $p = .001$). With a Client's Key worker much more likely to conduct an assessment in the Learning Disability sector, whilst in the Mental Health Service sector the assessment was conducted by whichever member of the team was available. There were no significant differences across sector regarding desire or need for more guidance, all sectors wished for more guidance.

Key points from the Staff Survey

- 98% of staff would like more guidance and training on the Mental Capacity Act and its implications for practice
- More information on standardised (or a range of) assessments recommended for use in certain groups/settings
- More guidelines on frequency, recording, and triggers for assessment
- More advice on best practice regarding who to involve in assessment
- Clearer and better communicated local policies and principles

What Service Users had to Say

A total of twenty service users were interviewed. Many of the service users interviewed talked about the range of decisions they make, from day-to-day choices to larger decisions about the future. Generally, people felt confident in their ability to make everyday decisions and believed that they were doing so capably, though a number of service users stated that it could sometimes be hard to make even the most basic of decisions. Only a few service users gave examples of the larger or more significant decisions that they were making in their lives.

The majority of those interviewed felt that they had enough involvement in making decisions. Many said they were happy with their level of input in the decision making process: that they were always consulted on decisions and generally felt listened to. However, a number of individuals did not feel so involved. A couple of service users took personal responsibility for this, saying that they did not always feel able to get involved with decision-making due to a lack of confidence in communicating their wants and needs. Others held those around them responsible for not involving them enough in decisions, feeling people did not listen to their opinion or would come to a decision without asking for their viewpoint.

Indeed, many of the service users interviewed said they could remember a situation in which people had made a decision on their behalf. For a few, this had been a positive experience and had alleviated their anxiety about making a decision. However, it was more usual for people to highlight negative experiences of people making decisions on their behalf and to discuss the distressing impact this had. Some service users talked of how the experience had made them feel uncomfortable, others talked about feeling powerless or useless and some talked about feeling annoyed, angry and frustrated. Usually these negative experiences had occurred while the individuals were in hospital: often when they had been sectioned under the Mental Health Act.

Key Messages from Service Users

A number of factors were identified by the service users as being helpful when expressing their wants and needs and making their own decisions. These were:

- **Communicating through preferred means** - having the choice to communicate in the way they feel most comfortable, whether this be verbal, through writing or other creative means
- **Being heard** - it was important to service users that the people around them really listened to what they had to say. By feeling listened to, they believed their opinions had been understood and were valued
- **Familiarity and trust** - trust was often built through familiarity with others and a feeling of knowing those around you well
- **Particular service and staff qualities** - it was felt that expressing ones' wants and needs is easier when staff are good communicators, good listeners, are down-to-earth and respond to individual needs. A warm, welcoming and safe service environment is also helpful

The factors service users' felt hindered them in expressing their wants and needs and making their own decisions were:

- **Lack of confidence** - service users said they were less likely to make decisions or express their wants and needs in situations where they felt unconfident. Some talked instead of trying to hint to others about what they want, without openly expressing it
- **Prejudice and stigma** - some service users with mental health problems felt disempowered by the prejudice and stigma they experienced as a consequence of their mental health problem, and believed this had an impact on their ability to express themselves and make decisions

What Carers had to Say

A total of six carers were interviewed. Some of these carers talked about the type of decisions the person they care for makes independently. These tended to be smaller, everyday decisions or those which one carer described as 'trivial' or with 'no serious consequences'. Only one individual gave an example of a larger or more significant decision made by the person they care for.

Some carers also talked of mutual decisions being made between themselves and the person they care for, following discussions about the available options. It was clear that these carers valued the input of the person they care for and endeavoured to involve them in the decision-making process. However, a couple of people acknowledged that they could sometimes guide or persuade the person they care for toward making a certain choice, particularly if they felt that they did not fully understand the decision to be made.

On occasion, some carers would go beyond guiding and persuading and actually make a decision on behalf of the person they care for. This was particularly pertinent in situations where an important decision (which could have serious repercussions for the person being cared for) was to be made. Some carers felt strongly that in such situations, they did not have a choice as to whether or not to become

involved, but instead saw their involvement as a necessity: a decision needed to be made and the person they cared for was incapable of making that decision, therefore it was their responsibility to intervene. Only two of the carers interviewed felt that the capacity of the person they care for changed or fluctuated; others felt that the person's capacity stayed the same.

Key messages from carers

- **Recognition** - Service providers should be able to demonstrate that they recognise a carers' role in the assessment of capacity and decision making process and acknowledge their familiarity and understanding of the service user.
- **Involvement** - Many carers are appreciative of the support they receive from services and particularly value the opportunity to discuss their situation and their concerns with others, to hear other people's experiences and to gain their advice.
- **Support** - Services should ensure that support groups are accessible to all carers and consider the potential barriers to attendance.
- **Impact** - Services should acknowledge the responsibility associated with being a carer and the impact this has on a carer's own life.

Conclusions

The project found an overwhelming desire amongst staff for more training and guidance on the issue of mental capacity and its assessment. There was also considerable variety in individual staff's and perceived organisational definitions indicating a need for more guidelines - or perhaps greater efforts at communicating existing guidelines - to provide better standardisation of understanding of capacity, assessment of capacity (how and when to assess), and best practice regarding who and when to involve others in assessment.

There is no standard test or assessment for capacity being used. The Act does introduce a standard, simple, test of capacity and the Code of Practice provides guidance on how to ensure individually tailored and appropriate tests for the person and situation. However, the great variation from staff in outlining principles of assessment needs to be addressed. The golden mean between prescriptive or restrictive recommendation and complete lack of coherence needs to be reached.

Service users clearly stated that whilst good practice does exist in the sector, more attention must be paid to supporting them to express their needs appropriately, to encourage confidence

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and to battle stigma (both within the sector and outside it).

Carers have much to offer staff and services in their knowledge and experience of the person they care for. Services need to recognise a carer's expertise and support the carers own needs in a completely accessible way.

Research with participants who lack capacity

Conducting this research was difficult in many ways, ethical approval was a long and difficult process, the project team modelled the guidelines set out for research by the Act. In terms of the practical lessons learned, the research team found that services vary greatly in their attitudes towards research involvement and consent. A researcher needs to make sure they are following the guidelines of the act even if the service is unaware of them.

In following the guidelines teams need to allow extra time to be set aside, informed consent is not a simple procedure with this group, and extra time and resources needs to be put in place to ensure fully supported consent. Translators, carer involvement, staff involvement all may be necessary and that can make working in the service harder and longer than usual.

Key recommendations from the project

- There needs to be a coherent strategy across sectors to communicate guidance and training on the Act for frontline staff. As well as training on issues such as good communication, supporting patient choice and user empowerment, person centred care and managing risk.
- There also needs to be similar work across sectors to ensure the provision of support and mentoring for practitioners to enable them to apply the Act in their everyday practice, with a focus upon supporting patients and users of services to make as many decisions as possible for themselves.
- An audit or evaluation of knowledge and training regarding the Mental Capacity Act would be helpful to identify areas and gaps that need to be filled
- Services must be able to demonstrate how they have involved service users and their carers, in the determination of the person's best interests.
- There needs to be more resources in place to support service users to make their own decisions (staff time, carer involvement, confidence building, and time taken around decisions).

To find out more about this project call the Mental Health Foundation Research Team on 0207 8031 100 or email us at mhf@mhf.org.uk

To download a copy of the 'Whose decision?' report visit www.mentalhealth.org.uk