

Summary of findings from the Whose decision? project

An exploration of the preparation for and implementation of the Mental Capacity Act in Statutory and Non-Statutory Services in England and Wales

“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)

Background

Mental capacity – or 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 therefore need to be made on their behalf. These include people with serious mental health problems, people with dementia and people with learning disabilities.

Sadly, the history of health and social care and treatment provided to people who may have lacked the capacity to make decisions contains many examples of how a diagnosis or disability has been used to prevent individuals from making even simple decisions for themselves. In addition, where someone genuinely could not make a decision for themselves (for example, consenting to medical treatment) their needs might have been ignored altogether or only catered for in the most basic of ways.

To protect against poor practice, the Mental Capacity Act 2005 (MCA) was initiated and it came into full effect in October 2007. The MCA can apply to anyone who is aged 16 or older in England and Wales and has five principles which should be applied in any situations where mental capacity is an issue:

- 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 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, a person who lacks mental capacity should be the least restrictive of their basic rights and freedoms

The research

Prior to the Mental Capacity Act coming into force, the Mental Health Foundation (incorporating the Foundation for People with Learning Disabilities) conducted a study which explored existing practices involving the assessment of mental capacity in services throughout England and Wales. Sixteen sites participated in this research and these sites consisted of a mixture of statutory and non-statutory services in both rural and urban regions. The sites consisted of adult mental health services, learning disability services and older people services. Within these sites, the researchers distributed a questionnaire to members of staff, which explored their knowledge of the issues surrounding mental capacity, their awareness of the

changes that the Act would bring about and any mental capacity training they had accessed prior to the changes in the Act. The researchers also conducted one-to-one interviews with service users and carers regarding their experiences of mental capacity issues.

Specifically, the research sought to address the following questions:

- How do staff and organisations currently define mental capacity and decide when it needs to be assessed?
- What training and guidance is currently available to staff regarding the Act?
- What is the experience of service users in being able to make decisions and make their choices known?

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- What is the experience of carers in enabling those they care for to make decisions and in making their choices known?
- What is the current experience of carers and service users of mental capacity assessment?

The researchers will return to the same sites in Autumn 2008 (one year after the Act came into force) and will explore whether any changes have been made or experienced within these services as a consequence of the introduction of the MCA.

Staff experiences of mental capacity

A total of seventy-three staff from sixteen services across England and Wales completed a questionnaire. When asked about their personal definitions of mental capacity, the majority of staff (83%) said 'an ability to make a decision'. Of these, more than half linked the ability to make a decision with the ability to understand information and to make an informed, logical or reasoned decision. A significant group suggested that mental capacity also included an ability to understand the consequences of a decision or an action. Staff were also asked about their organisation's definition of mental capacity. Only a small number (9%) said that they didn't know or were unsure of their organisation's definition.

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.

The majority of staff interviewed (59%) stated that they had received 'a little' training on mental capacity assessment; 36% stated they had not received any and 5% that they had received 'a lot'. When asked if they would like more training on the issue, 59% said 'yes a lot', 39% said 'yes a little' and only 1% said 'no'.

Service user experiences of mental capacity assessments

A total of twenty service users were interviewed across eight of the services included in this study. 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.

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

Carers' experiences of mental capacity assessments

A total of six carers were interviewed across four of the services included in this study. 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.

What is the experience of carers and service users in mental capacity assessment?

It was clear from the interviews that either a) formal capacity assessments were not being conducted in the services being studied or b) service users and carers were not being clearly informed that capacity assessments are being conducted. Only two of the twenty-one service users interviewed said that they had undergone a formal capacity assessment, while none of the carers interviewed were confident that the person they cared for had undergone a formal capacity assessment. Two of the carers said the person they cared for had had some form of assessment but they were not clear whether this was to assess capacity per se.

Some of the service users interviewed did have comments to make about the Mental Capacity Act and the changes it would bring. Those who did comment of the Act were positive in their contributions, stating that it sounded 'useful' or 'a good idea'. The suggestion of providing access to advocates was also supported. The only concern was

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that one individual felt it might not always be practical to nominate an individual to speak on your behalf.

Conclusions

A number of key messages were highlighted in this research. These were:

Emerging themes from staff

- 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 or 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

Emerging themes from service users

- Service users have varying preferences of how to express their wants and needs to others and service providers should allow service users to express themselves in the way they feel most comfortable
- Services should be able to demonstrate that they can ensure that service user opinions are valued and understood
- Service users are less likely to make decisions or express their wants and needs in situations where they feel unconfident. Services should encourage and

support service users to grow in confidence and help develop their abilities to make decisions with less support

- Prejudice and stigma can diminish service users' confidence and inhibit their ability to express their wants and needs. Services should work with service users and their families to tackle prejudice and stigma
- The quality of services and relationships with staff are important considerations when helping service users to make decisions.

Emerging themes from carers

- 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
- Services should be able to demonstrate that they recognise a carer's role in the assessment of capacity and decision making process and acknowledge their familiarity and understanding of the service user
- Services should ensure that support groups are accessible to all carers and consider the potential barriers to attendance
- Services should acknowledge the responsibility associated with being a carer and the impact this has on a carer's own life and should involve them

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

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