

Best Interests Decisions Study: Lay Summary

Introduction

The Best Interests Decisions Study was the first large-scale national research to find out about professional practices in best interests decisions made under the Mental Capacity Act 2005. The study was led by the Norah Fry Research Centre at Bristol University, in collaboration with the University of Bradford and a UK research and development charity, the Mental Health Foundation. The study was funded by the Department of Health and was completed in 2011.

What is best interests decision-making?

The ability to make decisions is sometimes called mental capacity. The Mental Capacity Act 2005 (MCA) sets out what should happen in England and Wales if someone is unable to make a particular decision for themselves – if they lack mental capacity. The MCA says that a decision made for someone who lacks capacity must be made in their ‘best interests’. The person making that decision is often a health or social care worker, and they must follow the MCA ‘Code of Practice’ – an official good practice guide to using the MCA.

Why we carried out the research

This research study aimed to find out more about how best interests decisions are being made, how far the Code of Practice is followed, and how helpful it is in real life situations. The study looked at:

- The types of best interests decisions being made in different situations (such as a hospital or a care home) and with different groups of people who may lack capacity (such as people with learning disabilities and people with dementia);
- The different ways that best interests decisions are made;
- What factors people making a decision take into account;
- What helps health and social care workers make a good best interests decision, and what stops them from doing that.

This is a summary of the main findings from the research. We have also written a full report which can be downloaded from the Mental Health Foundation website (www.mentalhealth.org.uk), the Norah Fry Research Centre website (www.bristol.ac.uk/norahfry) and (the Centre for Applied Social Research): <http://www.applied-social-research.brad.ac.uk/>.

How we carried out the research

We collected information about 385 best interests decisions made in four areas of England through an online survey of professionals and workers involved in best interests decisions. These decisions related to¹:

- 154 people with dementia
- 131 people with learning disabilities
- 107 people with mental health problems
- 75 people with brain injuries or a neuro-disability
- 21 people intoxicated with drugs or alcohol
- 17 people who were unconscious
- 5 people with other conditions or no condition

Telephone interviews with 68 of these people gave us a better understanding of what they had done and why. Of these, 25 also agreed to speak to us in person, face-to-face, and we were also able to speak to others involved in the decision. This allowed us to get a lot more detail about the way that best interests decisions are made.

Showing why a best interests decision is needed (assessing capacity)

A best interests decision can be made for someone else only if it can be shown that the person lacks capacity to make that particular decision at a particular time. Most of the decisions we looked at followed on from an assessment showing that the person lacked capacity (83.5%). However in some cases workers were unsure if an assessment had been done (7%), while in almost 10% of cases a best interests decision had been made, even when an assessment had shown the person had the capacity to make it themselves. This means that as many as one in ten best interests decisions appear to have been made without a proper legal basis.

People involved in best interests processes said that the most difficult part of the MCA was assessing someone's capacity. Despite this, there was good practice reported in giving support and chances to 'regain' capacity. Most assessments of capacity appeared to follow the guidance laid down in the MCA Code of Practice: many rightly showed a lack of capacity because the person was unable to understand either the nature of the decision or the potential consequences of it. Severely disabled people were more likely to lack capacity because they could not communicate a decision.

However, some of the reasons people gave for concluding that a person lacked capacity are specifically ruled out in the guidance: because of the person's disability, their history, diagnosis or illness (in 17% of cases), because the person was making an unwise decision (6%), or because of the person's age, appearance or behaviour (3%). The research also found other things that complicated assessments of capacity: for example, how able the person was to care for themselves, the strength of their personality or how vocal they were. People often mentioned 'insight' (the ability to understand the effects of an illness, or recognise one's own needs for care or support). A lack of insight was sometimes taken to mean a lack of capacity. This often happened with people who were less severely disabled, and when workers were keen to protect people from harm.

An assessment of capacity should always come before a best interests decision is made. We found that sometimes the assessment and the decision overlapped. This 'concertina' effect may happen because workers want to assess a person's capacity at the time a particular decision needs to be made, as the Act and Code of Practice suggests they should. In many cases there was a need to address an immediate risk to the person. We also found that workers often approached a situation with a decision or action in mind and saw the assessment as confirming their judgement that the person lacked capacity. In these cases the 'concertina' effect was about ensuring that everyone would be protected, especially where there were disagreements about what was in the person's best interests.

The research found a preference for assessments of capacity to be reached by consensus after different opinions had been aired, including expert advice where required. Those leading assessments said this helped them to think more deeply about a person's ability to make the decision for themselves. However, in

¹ Some people had more than one condition, therefore the number of conditions covered by the research (510) is greater than the number of decisions (385).

some services more junior staff either asked a senior colleague to carry out an assessment of capacity or assumed that it had to be done by a specialist.

Decisions about health care or treatment

Almost half (48%) of the decisions we looked at were about someone's health care. A decline in the person's health or a medical emergency often prompted the need for a best interests decision. In half of the decisions about treatment, the person's capacity had to be assessed on the same day as the best interests decision was made. Ambulance crews and intensive care staff were often involved in these urgent decisions. In decisions relating to less immediate treatment, health care staff relied on those close to the person – their family or care home staff, for example – to alert them about the need for action. Once the process started, good best interests decision-making was associated with health care staff sharing information and consulting as widely as possible.

Decisions about social care matters

About one quarter (24%) of the best interests decisions in the survey were about personal welfare or social matters, such as where someone should live and how they should be supported. Many of these decisions were prompted by a person leaving hospital. A majority, and particularly the decisions for people with dementia, were also about the potential risks of the person living on their own. We found few best interests decisions that resulted in someone living more independently than before.

Best interests decisions about a person's safety were rarely taken because of a single incident, but usually followed repeated attempts to protect them from either an inability to care for themselves, or putting themselves in unsafe situations, or spending money recklessly. In most of these cases a best interests decision came about because the person's behaviour was judged to have moved from being 'unwise' to being unsafe.

The Deprivation of Liberty Safeguards (DoLS) became law in April 2009 as an amendment to the Mental Capacity Act 2005. The safeguards protect the rights of people in care homes and hospitals who lack capacity to make decisions about care or treatment that restricts their liberty. Health or social care staff making a best interests decision that results in someone's liberty being restricted must seek authorisation before they proceed. Over a third of the decisions in the research potentially required such authorisation, yet some workers were unaware of the safeguards. Some decisions that restricted the person's liberty were made without authorisation and were influenced by the family's views. Of 15 decisions relating specifically to adult safeguarding, just over a third (6) resulted in restrictions being applied to the person, when authorisation may have been needed.

Decisions about property and financial affairs

We found that when someone lacked capacity to make a decision about their property or financial affairs, they often had capacity in other ways. Yet there was often a link between a financial decision and those concerning someone's health or social care; for example a decision about someone's welfare might trigger a suspicion that their money was being misused. Compared to other types of decision, the best interests process for property and affairs was often a slow, considered one that was more likely to involve a legal professional.

The time taken to make a best interests decision

The research looked at how long it takes to make a best interests decision. We found that urgent decisions were more likely to be about health care, while the ones that took longer were more likely to be about property and affairs, or about more than one matter. Urgent decisions were also most likely to be for people who were unconscious or who were under the influence of alcohol or drugs. Where there was disagreement about what was in a person's best interests, it was much more likely that the decision would be made over a series of meetings.

The research found that there can be delays in reaching a best interests decision because of the time taken to complete reports or organise meetings. A delay can be helpful in putting the person who lacks capacity at ease, giving them a chance to get more information about the decision and thinking through what the outcomes of it might be. But a delay can also mean that opportunities for successful outcomes are missed: we heard about some cases where someone's health was affected because of a delay in deciding about their treatment or care.

Taking responsibility for best interests decision-making

The Mental Capacity Act and the Code of Practice say that a named individual should take responsibility for making a best interests decision: she or he is known as the decision-maker. The research found that the tasks of leading a best interests 'process' (making sure the appropriate steps are taken to reach the final decision) and taking responsibility for the decision were not necessarily carried out by the same person.

Leading a best interests process included knowing what the Mental Capacity Act and the Code of Practice say should be done, getting the right people involved, organising any meetings that need to happen, and making sure that everyone understands what they need to do. Making a best interests decision was about being the person who took responsibility for deciding on the best course of action and involved weighing up the specialist knowledge, information, and opinions that could help to inform the final decision.

Our research showed that workers prefer to share the responsibility of being the decision-maker with one or more colleagues. For example, paramedics felt a "significant burden" if they were unable to share decision-making in urgent life-threatening situations. Only a small number of best interests decisions were made by a sole decision-maker (7%), and interviews confirmed the reluctance of participants to take on this responsibility despite acknowledging the importance of it being a clearly identified role.

How best interests decision-making processes work

We found that everyday, less 'serious', and some sensitive matters, such as personal hygiene, could often be resolved through informal conversations. Where this happened it was important that the process was recorded. However, most people preferred to have some type of meeting, even if there was preparation and work involved outside the meeting. Having best interests on the agenda at regular team meetings made it less likely the issue would be overlooked and ensured that actions were followed through. It helped to have someone identified clearly as the person taking responsibility for the decision, and that was particularly vital in urgent situations.

The research showed that a best interests process may involve a series of linked decisions. Thus, a major best interests decision, about moving home, for example, can give rise to a series of smaller decisions - about where to live, with whom, how the home should be decorated and so on - which are necessary for the larger decision to be carried out. These smaller 'sub-decisions' are often a way of involving people in choices about their own life even if they lack capacity to make the big decision.

People did not always agree about the person's best interests, and so conflicts could arise. This was especially true where a family member was suspected of causing harm to the person who lacked capacity, or where a family member's own needs for help had to be taken into account when making the decision. Being able to manage such conflicts was therefore an important skill for people leading a best interests process.

Involving the person who lacks capacity

Even though someone might not be able to make a decision for themselves, they should be involved as much as possible and their views and preferences taken into account. In over three-quarters of decisions (80%) the known wishes and feelings of the person were said to have been taken into account. However, this did not always happen through meetings. Some people could become distressed at meetings if they disagreed with the decision being made, while others were not interested in attending or may not be able to contribute in a meaningful way. Most of the people not involved in a meeting about their best interests still had a say by being supported outside of the meeting, where their communication needs could be better met and more time could be taken to explain the decision to be made.

Involving others who know the person

The Code of Practice says that decision-makers should consult with people who know a person who lacks capacity well when weighing up what is in their best interests. This happened in more than two-thirds of the decisions we looked at (69%). In the remaining cases it was either not possible to consult with someone (perhaps because it was an emergency) or it was inappropriate to do so (perhaps because of a safeguarding issue involving the family).

Familiar people often had important knowledge about how best to communicate with the person lacking capacity and this could be vital in urgent situations. They could tell decision-makers about the small details in people's lives which mattered to them. Health and social care workers also understood that many decisions could only be put into effect if those close to the person are in agreement and give their support. Decision-makers had to weigh the value of other people's views and opinions by taking into account things like their closeness to the person who lacked capacity. People taking part in the research felt overwhelmingly that appropriate people had been consulted (88%) and that their views had been taken into account.

Independent Mental Capacity Advocates – 'IMCAs'

An Independent Mental Capacity Advocate (IMCA) must be appointed to represent someone who lacks capacity to make certain serious decisions where there is no one appropriate to consult. IMCAs played important roles in many cases. However, we found some confusion about when an IMCA can be appointed and about the role they are expected to play. Some professionals making best interests decisions felt that IMCAs should represent the views of everyone involved in a best interests decision, not just the person who lacks capacity. Others believed, wrongly, that IMCAs could be brought in to adjudicate disagreements. In a few instances an IMCA took on decision-making responsibilities rather than just being consulted.

Making the decision

People taking part in the research were generally satisfied that best interests had been decided well by thinking carefully about an individual's quality of life, and what mattered to them. Creative thinking and having good options helped in this. A strong guide was often what a person did actually want, or would have wanted, if they had capacity to decide for themselves. But while we found that decisions generally took into account all the information gathered during a best interests process, only three quarters of health decisions were made on that basis.

There were some constraints on the decisions that could be made. They often had to take into account risks to the person, and workers had to balance respect for the autonomy of their clients or patients and the need to override it on occasions. Decisions also had to be made in the real world, and so often involved a degree of compromise, for instance where a family carer's needs had to be considered alongside the best interests of the person lacking capacity.

Keeping a record of what happened

Best interests decisions for everyday matters were sometimes recorded informally, in daily staff records, or attached to a care plan. About one third of decisions were recorded in formal notes and a further third on forms designed for the purpose. Although these forms were often available to both health and social care workers, the latter were more likely to use them. The forms were appreciated because they gave the best interests process a clear structure, although sometimes they lacked space for the detail that workers wanted to record.

Outcomes

In the vast majority of cases the decision led to an action or treatment being carried out in the person's best interests. A successful outcome was said to do one or more of the following: please the person lacking capacity; protect them from harm; protect staff. In a small number of cases, the decision had not yet been put into action because of people not working together to make it happen, a lack of resources or availability of a placement, someone's refusal to go along with the decision, or poor health of the person lacking capacity.

The research showed that good communication, sharing information and different services working together all helped to produce good outcomes in the short term, but that a means of reviewing outcomes was required to monitor best interests in the longer-term.

People with dementia and best interests decisions

A significant number of decisions we looked at were made for people with dementia who lacked capacity (40% of the online survey responses involved someone with dementia) although we also heard about older people without a diagnosis of dementia who were found to lack capacity because they were frail or had a physical illness. Most decisions for this group related to a change of accommodation. A smaller number of decisions were about safeguarding but people with dementia were less likely than other groups to have best interests decisions made about their health or medical treatment.

People with dementia seemed to be treated differently in best interests processes compared to other impairment groups. The ability to carry out an action was often confused with the ability to decide on it. It appeared that some workers made assumptions about capacity based on the fact of the person having dementia; tests of dementia were mentioned as if they were tools for assessing capacity.

Outcomes for people with dementia also varied, often limited by resources, availability of home care, and the need to consider relatives. Temporary admissions to care homes were sometimes made permanent, without the agreement of all parties concerned, and DOLS applications were only made in a minority of cases.

People with learning disabilities and best interests decisions

A third of the decisions (34%) concerned people with learning disabilities. Frequently these decisions were about health care, but a health problem often revealed other decisions that needed to be made on the person's behalf. We found that people with learning disabilities, more than other groups, were likely to have their best interests considered by mixed teams of health and social care workers.

People with severe or profound learning disabilities were sometimes assumed to lack capacity to make a particular decision based on a long-standing general assessment of capacity. However, people with learning disabilities as a group benefited from good assessment practice that looked at a person's ability to understand, weigh up and communicate a particular decision. That was in line with the Code of Practice. While they were less likely to be invited to best interests meetings, their views were taken into account in other ways through one-to-one communication, real life experiences and observation, accessible information, person centred planning and greater involvement from family members and others.

People with mental health problems and best interests decisions

People with mental health problems were the third largest group in the research and typically, their best interests were considered in relation to their mental health needs. Their capacity was more likely to be assessed in urgent situations and the best interests process was often about the risk people with mental health problems posed to themselves or others. However, decisions about a change of accommodation for this group were considered over a longer period than for other groups.

Several specific issues about assessing capacity emerged for people with mental health problems, including fluctuating capacity, the effect of mood on capacity, and an inaccurate perception that being very vocal shows capacity. Effective best interests decision-making for this group was marked by informality, quiet or calm contexts, and by the involvement of trusted and familiar people.

People with neuro-disabilities and best interests decisions

This group was under-represented in our research, so our findings here are more tentative. Family members were regularly involved, and had strong and important roles to play in best interests processes. Clear information about medical decisions for this group was vital.

It seems likely that there are different issues relating to capacity for people with neuro-disability and those with brain injury. The sudden change in capacity in a person who has a brain injury continued to be hard to accept, even after a period of time, for those close to the person. For some with degenerative illnesses, the process of deterioration can also make it difficult to assess when he or she loses capacity to make a particular decision.

Conclusions

The Mental Capacity Act gives health and social care workers a legal basis for acting when someone cannot make a decision for themselves. The research looked at the range of best interests decisions being made and the prompts to this happening, such as changes in someone's health or the need to protect someone from harm. It also found that one decision often requires others to be made and these may need to be managed quite differently.

Identifying that the person was unable to make a decision by assessing their capacity was a concern for all the professionals in this research, although most were following the Code of Practice. We found a significant minority of best interests decisions being made for people who had either been shown to have capacity, could be supported to make decisions with help, or who had been wrongly assessed as lacking capacity. There are particular concerns about the use of ineligible criteria for determining capacity in some dementia services. More clarity about key issues such as 'unwise' decision-making and 'insight' might help address some of these problems. Similarly there was some confusion about when an authorisation for DOLS should be sought.

The research has shown that there are different ways of making best interests decisions and roles that have emerged to make the process work. While these do not breach the spirit of the Code of Practice they are not currently reflected in the training and guidance that is available to health and social care workers. We found that generally the right people are involved in decision-making, although there was some confusion about the role that IMCAs play, and we heard about good practice in involving people who lack capacity in the decision-making process.

Successful outcomes flowed from most of the best interests decisions we looked at, but there were delays in putting them into action in a small number of cases. Workers were also faced with dilemmas about balancing the autonomy of people who lack capacity with the need to ensure their safety and the wider needs of their families.

Recommendations

The research has implications for policy and practice about mental capacity and more widely for the education and training of health and social care professionals. Key recommendations for changes in these areas are summarised below.

Recommendations for policy

- The MCA Code of Practice should be revised in relation to: unwise decision-making; how ‘insight’ relates to mental capacity; and the relationship of best interests to adult safeguarding
- New case studies should be produced for the MCA Code of Practice covering: more complex situations; consensus or joint decision-making; how best interests processes are dealt with in teams and in care planning
- Terms used in the MCA Code of Practice should better reflect roles identified by the research, such as ‘best interests’ leader
- Gaps in practice, such as the apparent under-use of Deprivation of Liberty Safeguards, need to be highlighted
- Successful best interests practices should be listed in guidance, such as separating out different ‘layers’ of decision making
- Relevant guidance should be updated to take into account the way capacity issues affect the management of risk
- The Department of Health should work with health and social care providers to develop mental capacity assessment and best interests pro-formas
- Department of Health policies and guidance about other areas of health and social care practice (such as personalisation) should be updated to take account of any changes to mental capacity guidance resulting from the recommendations set out above

Recommendations for commissioning

- Advisors or leads for mental capacity should be appointed and funded in every local authority area to support best interests practice across health and social care services

Recommendations for professional education and training

- Local trainers should develop case studies that reflect complex, real-life situations and the common errors made when assessing capacity
- The Social Care Institute for Excellence should revise its training materials so that they are based on the different ‘models’ of decision making identified in the research
- Training materials should include examples based on situations relating to specific contexts, rather than using generic examples
- The training needs of mental health staff should be addressed, in particular to clarify the relationship between the Mental Health Act and the MCA
- Professional health care education should address situations similar to those highlighted in this report

Recommendations for practice management

- Health and social care services should be audited regularly for compliance with the MCA and DOLS. Compliance should be monitored by the Care Quality Commission
- Local mental capacity leads and commissioners should find new ways to help care home staff and management improve practice in assessing capacity and managing everyday best interests decisions
- Care homes should review assessments of capacity and best interests decision-making on a weekly basis. They should ensure that all staff are able to undertake capacity assessments themselves, rather than contacting specialists for that purpose
- Guidance for practitioners about the use of IMCAs needs to be reviewed and revised

Recommendations for future research

- Further research should be undertaken to understand more about the views and experiences of people lacking capacity, and their family carers
- Further research should be undertaken to investigate best interests in relation to everyday decision making and dealing with disagreements and disputes that arise from best interests decisions

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