Using the Mental Capacity Act in complex cases

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Abstract

Purpose – The purpose of this paper is to explore the way that practitioners apply the 2005 Mental Capacity Act (MCA) in complex cases involving people with learning disabilities who cannot make some key decisions by themselves. Like many qualitative studies it began with a felt sense that practitioners were struggling to apply the clear framework set out in the Act to real life situations, and that some of the decisions they were faced with did not fit neatly into the linear, cognitive model of decision making set out in the MCA and its accompanying guidance.

Design/methodology/approach – The study was conducted under the aegis of the Office of the Public Guardian (OPG) during 2010-2011. A number of “complex” cases were obtained from Social Services, Primary Care Trusts and other organisations and subjected to thematic analysis. The current paper focuses on the 16 cases that involved people with learning disabilities.

Findings – A number of issues were identified that underlay the complexity of the cases examined. The cases drew attention, in particular, to the way in which practitioners were confronted with mounting concerns as opposed to single, discrete decisions, with the risk that decisions could be delayed until positive choices were much less available.

Originality/value – The aim of the study was to support the use of the Act in these situations and to give practitioners confidence in applying its principles across a wide range of diverse circumstances. Although the original study specifically related to the English legislation, the factors that led people to consider a case “complex” would apply equally in other jurisdictions. The study also shed light on difficulties that arise when intervening in less formal ways.

Keywords England, Legislation, Learning disabilities, Social care, Mental Capacity Act, Best interests decision making, Complex cases

Paper type Research paper

The Mental Capacity Act (MCA) enshrines a presumption of capacity in law so that the onus is always on someone intervening to demonstrate that a person lacks capacity rather than requiring them to meet some test or threshold that proves they can make their own decisions. The Act also introduced a decision-specific framework so that a person who struggles with decisions in one arena can maintain their autonomy in others. Hence, citizenship rights are not removed from someone because they cannot make all decisions for themselves and these safeguards were welcomed by user groups and advocacy organisations during its passage into law. It also underpins rights guaranteed by the 1953 European Convention on Human Rights and is consistent with principles set out in the United Nations Convention on the Rights of Persons with Disabilities 2006.

The MCA has a number of components:

- First, it sets out principles to guide people who are assessing capacity and/or making decisions on behalf of others.
Second, it sets out a decision-specific definition of capacity and a test for assessing whether a person can, at a given time, and with appropriately accessible information and "all practicable support," make this decision for themselves.

Third, it provides a range of instruments that people can use to state their intentions in advance and designate who they wish to administer their affairs and/or act for them in making welfare decisions, at a future time when they may lack capacity: this they can do through granting a lasting power of attorney in advance or, if these arrangements have not been set in place, the court can appoint a deputy to act for them.

The MCA is based on five core principles, the first three enshrining a person’s right to make decisions for themselves unless it can be shown that they are unable to do this for themselves and the last two setting out essential guidance for anyone acting on behalf of someone they have assessed as lacking capacity. The principles are stated as follows:

1. A presumption of capacity – 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.

2. The right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions.

3. That individuals must retain the right to make what might be seen as eccentric or unwise[1] decisions.

4. Best interests – anything done for or on behalf of people without capacity must be in their best interests.

5. Least restrictive intervention – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

Hence, the MCA tries to set up a do-it-yourself model that allows sensible decisions to be made by those closest to a person who lacks capacity and most involved in putting arrangements into operation. Only highly complex, serious or contentious cases are subject to court hearings.

Once it has been decided that a person is not able to make a decision for themselves then a designated decision-maker is responsible for acting on their behalf guided by responsible professional opinion and by what is deemed to be "in their best interests." Sometimes it is not clear who the decision-maker should be and the decision does not necessarily fall to the person who assesses their capacity. So, for example, a consultant might take a decision about surgery, or a care manager about accommodation, but they might both be guided by a psychologist’s view of whether the person has capacity in these areas. Decisions should then be put into effect in a manner which imposes the least restriction on their "rights and freedom of action." But this is not necessarily the same as doing what the person wants even though decision makers are urged to take account of the person’s stated wishes as far as these can be accommodated.

The twin aims, of maximising the decisions a person makes for him or herself, while also creating a mandate for others to act on their behalf, but in their best interests, can lead to an uncomfortable switch especially in situations where a decision-maker has to use elements of control or restraint, albeit responsibly, to lead the person down a particular route. This switch from facilitator to active decision-maker is a shift that health and social care workers struggle to make, in relation to vulnerable people directly and to their families and informal carers. Judging when the time is ripe for persuasion to give way to this more proactive, and authoritative role is complicated even when it is clear that the responsibility for what has to be done has passed into their hands.

This framework allows most issues to be resolved by the person and their immediate circle and, in general, formal arrangements or hearings are avoided where possible. The MCA is administered by the Office of the Public Guardian (OPG) and adjudicated by the Court of Protection. Matters may be referred to the court when:
- there is a dispute around a finding of incapacity;
- there is disagreement between family members, carers and/or professionals as to the person’s capacity;
- the person concerned is expressing different views to different people, perhaps through trying to please each or tell them what s/he thinks they want to hear;
- the person’s capacity to make a particular decision may be subject to challenge, either at the time the decision is made or in the future;
- there may be legal consequences as a result of a finding of in/capacity; and
- the person concerned is repeatedly making decisions that put him/her at risk or that result in preventable suffering or damage.

The threshold for referral to the court is set at a relatively low level and not hemmed around by qualifiers to ensure that no-one is barred from bringing a challenge, even where it is the person’s capacity that might be in dispute. The MCA offers particular safeguards when decisions are being taken in relation to serious medical treatment and changes of accommodation but it is not limited to these matters and the decisions that had to be made in the cases submitted to the project included issues about relationships, family obligations, pregnancy and abuse as well as these already well defined issues.

About the study

The study recruited 11 agencies and invited them to submit details of up to three recent cases that they had considered “complex.” These consisted of:

1. four social services departments;
2. three health trusts (one PCT, one acute trust and one mental health trust); and
3. four voluntary agencies (two national campaigning groups, one provider of services and one advocacy provider).

In addition to this, six case workers from the OPG submitted cases as did the Master of the Court of Protection. In all, 60 cases informed the work, alongside four expert consultations, including two individuals with extensive experience of acting as an Independent Mental Capacity Advocate (IMCA). The cases were anonymised throughout. The study used qualitative methodologies, guided by grounded theory and participative research, to analyse the characteristics of those cases that had contributed to their being seen as complex. As a model emerged, it was tested and developed through a workshop attended by the agency representatives. The programme of work led to the publication of a report outlining these complicating factors (Brown and Marchant, 2011), a paper specifically considering the role of emotional stability in decision-making (Brown, 2011) and a collection of composite case studies designed to be used in training and case discussions[2].

The study included decision making in relation to all client groups and across the whole lifespan as the MCA addresses decision making for people who have, but then lose, capacity as they age; people who lose capacity as a result of catastrophic injury; those whose mental health difficulties may sometimes cut across their ability to manage their affairs and people whose intellectual disabilities, from the outset, have compromised some areas of their decision making. This paper therefore benefits from the analysis that was conducted across all client groups but focuses in on those cases that concerned people with learning disabilities so that we can understand how their real-life difficulties sometimes get lost under the radar of the MCA, or become convoluted once it has been applied.

This does not mean that their issues were fundamentally different – people with life-long learning disabilities also experience mental health difficulties, are subject to accidents and injuries, and may lose capacity as they age. The MCA has provisions that allow them, in common with others, to state their wishes in advance through the drawing up of lasting powers of attorney or advance statements that set out how they want to be treated if they
experience crises. None of the people with learning disabilities whose cases were submitted to the project had been assisted in using these provisions.

The cases submitted to the project did not purport to be representative of all cases addressed under the Act but more symptomatic of a few cases, held by each agency, that appeared to trouble those with decision making responsibility and that seemed to defy easy resolution. Hence the primary aim of the work was to assist services in applying the legislation in a timely way even, indeed particularly, in situations that were not straightforward.

Complex needs of these individuals

Out of the total 60 complex cases referred to the project, 16 concerned people with learning disabilities. All the cases were used to identify themes and generate the model of complexity but this paper focuses particularly on the people with learning disabilities. They tended to be in young adulthood, and had an average age of 35 and a median age of 30. Of these one was married and ten were single (five people’s status was not specified). Two people lived with their parents in the family home, one in an institution, five in learning disability residential care homes and seven in their own home with a partner or family member (one person’s place of residence was not specified).

In addition to their intellectual disabilities, these 16 individuals were contending with multiple difficulties and diagnoses (several with more than one) which we grouped together as follows:

- Physical difficulties – incontinence/need for assistance with toileting (6), mobility (6).
- Mental health issues – attention deficit hyperactive disorder and autistic spectrum disorder (1), anxiety (2).
- Difficult behaviour – challenging behaviour/rapidly changing moods (1).
- Medical conditions – acute respiratory infection (2), cancer (2), epilepsy (4), cerebral palsy (1), asthma and eczema (1).
- Family issues – domestic violence (2).

These issues contributed to concerns about when and whether to consider their decision making under the MCA, how to assess their capacity and how to deliver outcomes that would be in their best interests. The picture that emerged was of a group with complicated and inter-related needs, in some cases difficult relationships, who were coping with difficult situations, over and above their learning disability.

A model of complexity, set out by the Council of Europe (Brown, 2004), defined a person as having “complex support needs” if they had a high level of need not only within one domain but across domains. Our analysis of the cases submitted to this project was consistent with this, highlighting how it is often the interaction between, as opposed to the extent of, a person’s needs that makes support complex.

Complicated decisions for these individuals

The decisions that were under consideration in each of these cases, were as follows – five medical decisions, three financial matters, one decision about the family’s management of their care, one cluster of decisions about a family managing care that was complicated by financial issues, five decisions primarily about accommodation and one regarding how to deal with challenging behaviour. 14 of these people lacked capacity in most areas of their lives with two presenting a more contentious picture and/or fluctuating levels of capacity. Best interests was clear for one of those people, it was disputed for another, not properly assessed for five and “complicated” for five.

In three of these cases a safeguarding alert had also been raised and an IMCA was appointed in four cases. Five cases were referred for a court hearing and other legal remedies were the appointment of a court visitor in one case, and a deputy/receiver in two.
The OPG took an active role in one case and other legislation was brought to bear in some cases, including the Deprivation of Liberties (DoLs) provisions within the MCA, the 1983 and 2007 Mental Health Acts and the 1967 Abortion Act.

Factors that created complexity

We identified 30 issues that created complexity at different stages of the decision-making process[3] and we grouped them chronologically to help us think through each stage-referral, assessment, complicating conditions, ascertaining best-interests and putting decisions into practice. These factors are set out in relation to each of the cases involving someone with a learning disability in Table I.

Concerns and how they come to light

The way in which concerns came to light was key to referral and gatekeeping. A key issue discussed by all the workers was that decisions rarely present in a neat and orderly way and workers are more often concerned about a range of issues over some time as they grapple with when to apply a formal process of decision making. The MCA is predicated on there being a clear and well-formulated decision to be made. But six of the cases were characterised by these mounting concerns and sometimes there was no clear point and/or no obvious time frame that tipped the issues into this formal process. A third of the cases involved people and/or carers who shrank from making decisions, avoiding or withdrawing contact with agencies. This highlighted a raft of cases where service refusal was a central issue. The early stages of the process suggested that decision making should be thought of as a process requiring active support rather than a hands-off approach until this could not be maintained. Timely intervention might have prevented painful choices later because by the time signals had grown loud enough to be heard, some of the issues had become confrontational and options had closed down.

The case of Mr V provides a useful illustration of this conundrum. It involved a young man with epilepsy whose mother had decided that his seizures were brought on by stress and that contact with professionals was inherently stressful and therefore to be avoided. The man's mother was isolated and vulnerable herself and from a relatively disadvantaged minority ethnic community. Over several years she effectively kept her son immobile in a darkened room at home, removing him from day services and other community activities with very deleterious consequences for his mobility and mental health. Professionals did not abandon him in this situation, they worked as creatively as they could to provide a package of care at home, and tried to support the mother so that she could continue to care for her son. Eventually they reached an impasse over the issue of medication for Mr V's epilepsy that needed to be reviewed. This case was eventually referred to the court and an order was made but a lot of water had flowed under the bridge by that time and this young man, who had been sociable and physically fit when he left school, had become progressively more disabled over the years that he was confined to the home. The medical issue was effectively used as a pretext for removing him from the family home when actually a host of smaller issues could have been the focus of a challenge as to whether his carer was acting in his best interests much sooner in this trajectory. It was clear that the social and psychological consequences of this enforced isolation were as, or more, damaging over time than some of his health care issues. But this is difficult because practitioners will often seek to delay confrontation even when doing so risks compromising longer term options.

The switch that has to occur for practitioners to change from this supportive and often deferential approach to family carers, into a place where they are going to make a robust challenge on behalf of a vulnerable person, is the most difficult judgment call for social care staff to make. It is one that is often fudged and allowed to slide if mental capacity and best interests issues are not raised around lower profile issues. Could, and should, this family have been challenged about the refusal to let their son attend the day centre, or go to a social club, long before there was a medical issue to provide “cover” for the eventual high profile intervention?
### Table 1 Factors leading to complexity in LD cases

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<td>26</td>
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<td>X</td>
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<td>✓</td>
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<tr>
<td>Changes in network over time</td>
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<td>NT</td>
<td>X</td>
<td>✓</td>
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<td>X</td>
<td>X</td>
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<td>X</td>
<td>✓</td>
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| Note: <sup>a</sup>Not in this time frame

<sup>a</sup>Not in this time frame
So timeliness also matters. Often people let relatively minor issues slide because they did not seem to imply major risks. However, when these risks had been allowed to run on, often because the person disengages rather than through active choices, the cumulative damage makes later decisions more pressured. For example, someone with diabetes who makes wrong choices about food may be left until confronting their by then urgent weight problems is critical, and the options open to them very limited. Just as, in the field of challenging needs, we accept that disengagement is not a helpful “choice,” so we must think about being proactive if a person’s default position is to “not decide” especially about issues or relationships that cumulatively restrict their options and/or are bound up with longer term risks. This delaying of decision making seemed more prominent in cases where the decision was tied up with other considerations, because changing one thing so often unbalanced others. Almost half of the cases involved decisions that were wrapped up in other matters so that resolving one would upset another area of the person’s life. Ms W, for example, was living against a backdrop of domestic violence but she risked losing contact with her culture and community if she was moved from home so there was a trade off for her receiving more consistent and safer care. As workers were unsure if this was a price worth paying they waited until matters had escalated, effectively forcing their hand.

Capacity that is disputable

We then identified a number of issues that made it difficult to assess capacity and that suggested the need for training to focus less on the technicalities of providing accessible information (this is usually part of a skilled practitioner’s repertoire anyway) but more on how to deal with family dynamics, manage resistance or even aggression on the part of the individual or a family member and take the lead in consensus-building. The British Psychological Society (2006) guidance on assessing capacity remains the most helpful information for professionals about the practicalities of undertaking an assessment that we accessed. It explains the difference between three types of assessment – a diagnostic test, an evaluation of outcomes (that is making a judgment that a person lacks capacity because of the unwise decisions they are seen to make) and a functional, decision-specific test as advocated in the MCA. In fact these may be less distinct than they seem and all three are often wrapped up in a comprehensive assessment. Mr H, for example, who has autism was assessed by a consultant psychologist who brought together a knowledge of autism, its potential to distort a person’s decision making especially when a decision would presage a major change in living arrangements, and a consideration of the young man’s history in terms of how he had been managing in his family up to this point in time. These more relational issues were brought to the fore in what was an excellent assessment process because they were as germane to the decision at hand as Mr H’s cognitive abilities when considering whether Mr H. should move away from his family into a more independent living situation.

Conditions that complicate

In the broader study we also considered the impact of particular conditions that seem to override cognitive capacity in sometimes unpredictable ways. These included problems of addiction, frontal lobe damage, conditions such as Prader-Willi syndrome (a chromosomal condition that compromises a person’s ability to manage their food intake but not necessarily their ability to manage other issues – see Holland and Wong, 1999), the intransigence that sometimes accompanies autism (Blastland, 1996) or anxiety and eating disorders. We found that practitioners were unconfident in interpreting the impact of such conditions on mental capacity. This raft of issues is written up more fully in Brown (2011).

Constraints on best interests decisions

There followed a group of issues that complicated the determination of best interests. Once a person has been deemed to lack capacity in relation to a particular decision then the decision-maker is bound to make it in that person’s best interests. This requires a shift of perspective and, sometimes, if the person is resistant and/or vociferous it casts a shadow over the decision-maker who has to take the person’s view into account but not be
constrained by it. This tension has been the subject of recent case law that has been written up in the full report of the research.

Even when it was clear that a case had become one that required a best interests decision be made on behalf of the person, the decision-maker was often not clear about their responsibility and there was confusion about who could and who should assess the person’s capacity in relation to the particular issue(s) at hand. Often the person responsible for the decision seemed to hand over responsibility to a doctor or psychiatrist who might have been brought into help in the assessment but was not the person most knowledgeable about the decision to be made. The spread of actual decision makers included six care managers, five medical doctors, one care provider, two OPG/Court of Protection workers and, in two cases, collaborating “networks.” This confusion led to some buck-passing and some buck-returning! But it also led to assessments that, unlike that of Mr H described above, were peremptory, decontextualized and/or overlooked the relationship dynamics that were at the core of the matter, including whether another person might be being dominating to the extent that it cut across valid decisions made by the more vulnerable or dependent person.

Good teamwork, of the kind that pertained in Mr H’s case, provided an antidote to this kind of unhelpful separation. The examples of assessment that are offered in the MCA guidance focus on making “static” information accessible when it is this kind of dynamic situation that is really testing, requiring as it does a careful blend of social and emotional information, and space to explore intentionality and mutual obligations. Mr H was able to make an informed choice to move on; in Ms W’s case a decision had to be made on behalf of a young man who was being badly impacted by domestic violence. Leaving home for her also meant leaving her community and potentially rupturing important cultural and religious ties so this was necessarily sensitive. The decisions that were rooted in flawed relationships were often the ones where practitioners found it most difficult to assess capacity. Where the assessment led to the need for a best interests decision, they were hard calls to make on behalf of the person.

Constraints on best interests in these cases varied but included the fact that the person’s best interests conflicted with the needs or wishes of others, and several cases where the person responsible for making the decision was “daunted.” A clutch of cases involved end-of-life care, and some of these decisions had to be made within a very tight time frame. Another involved termination of a pregnancy and even though everyone in the network agreed that the woman concerned did not have capacity and that ending the pregnancy would be in her best interests, they faltered until it was too late to make that choice.

**Contingencies when trying to implement decisions that had been made**

Once decisions had been made there were difficulties in overseeing the way they were put into practice. Often no-one had identified trigger points that would signal a need to revisit the issues and/or to reconfigure arrangements that had been put in place around the person. In six of these cases a change in the person’s network, after a best interests decision had been made, meant that the situation was not stable or safe for them. Funds were intermingled in four cases again presenting a delicate set of choices to be (re)made. Some of the cases being managed by the OPG involved situations that had tipped over into exploitation; others involved a person’s benefits becoming a mainstay of the family’s income in ways that precluded the person from moving on at their own pace. In situations where large damages awards had been paid there were concerns about the person’s care becoming a “cottage industry” and/or that over time good intentions would be corroded and lead to neglect. Great sensitivity was needed in these situations because there had often been trauma for the family as well as for the disabled person especially in situations where there had been a sudden onset of disability or a serious accident. In relation to people with learning disabilities there were cases where a parent had made arrangements that were hard for siblings to honour, and one case that bordered on fraud where the family of a man with learning disability had given money to a residential home owner as part of an agreement that care should be provided when later this was compromised. Health problems of relatives undermined their ability to provide the care that they had agreed and sometimes a change in their relationship status impacted...
on the family member’s willingness or ability to provide care over time. Care arrangements cannot be set in stone, but some stability needs to be achieved on behalf of the person who lacks capacity.

**Different agencies at different stages**

Each agency tended to struggle at different stages of the process. Social services found themselves acting as gatekeepers, health staff as assessors and the court officers as managers and enforcers as well as final arbitrators. Health and social care issues were often intertwined and matters were handled better where they were able to work together. This was generally accepted over issues that arose in the context of hospital discharge. Other systems also needed to be engaged where this was appropriate and some of the cases had been the subject of a safeguarding vulnerable adults (SVA) alert. This did not necessarily imply that there had been deliberate or malicious abuse, merely that this was one way of structuring shared decision making. In some authorities this may also be an administrative necessity in that MCA, DoLs and SVA sit under the same organisational umbrella. Other cases, despite concerns about wrong-doing, had not been routed through the SVA route.

**Concluding remarks**

The cases submitted to the study epitomised complexity. The initial process of referral was often the most significant stumbling block. “Decisions” do not present themselves in neat packages and many of these cases involved situations of cumulative risk or neglect over many years with intervention being delayed while the professional network prevaricated. Others involved decisions that were too daunting for a single individual to make. Where there was urgency, especially in relation to serious medical treatment and/or end-of-life care, professionals had rushed and sometimes ignored the need to bring family members with them, suggesting that good practice should involve more proactive advanced planning, where possible recorded in advance statements, in which these crises could have been anticipated. Where decisions were being taken against a backdrop of family conflict this had to be factored into the decisions at hand and confronted directly instead of being used as a reason to back off.

The issue of mounting concerns, as opposed to single, discrete decisions is not mentioned in the code and this seems to be the most glaring omission in the light of the cases submitted to this study. It warrants considerable guidance to social care staff in particular, and extends into debates about self-neglect and service refusal (Scourfield, 2010; Keywood, 2010) that have been the focus of recent literature and several high profile serious case reviews. The guidance needs to address the way concerns are formulated offering examples of how inter-related issues can be organised into a hierarchy and showing what “level” of decision should be the focus, debating whether a number of difficulties should be bundled up into one “matter” to be deliberated by professionals or brought before the court.

The MCA prioritises enabling people to make decisions that they can make wherever possible and its rubric highlights the presumption of capacity unless this can be demonstrated otherwise. But at the other end of the continuum many of these cases showed that people were being left to manage when they were not able to in important ways and that this left small matters to escalate over time. Although the MCA is predicated on the notion of there being a single, clearly boundaried decision on the table, these complex cases were typified by messy, difficult and sometimes cumulatively harmful relationships. Calling time on these situations before it was too late to be able to make positive choices on the person’s behalf, was a judgement call not sufficiently covered in guidance or training. But it was clear that in many of these situations standing back and leaving a person progressively more out of their depth left fewer options. This is not autonomy as you or I would recognise it.
Notes

1. A series of unwise or high risk decisions might lead those supporting an individual to question their capacity anew. The MCA protects a person’s right to make an unwise decision but not to make it unwisely, if that means not weighing up the information and issues in reaching their decision.

2. The case studies, and notes on using them to structure a team discussion and/or training workshop can be found at: www.canterbury.ac.uk/social-applied-sciences/ASPD/documents/Decision-makingusingtheMentalCapacityActincomplexcasescasestudiesforuseinstaffdevelopment.pdf

3. There were actually 31 issues as cases that got caught up in other jurisdictions also created difficulty but none of the cases discussed here were affected by this.

References


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