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Mental Capacity Past, Present and Future: An overview

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In this chapter

This chapter provides an overview of mental capacity, looking at:

- the nature of mental capacity and factors that can affect it
- the evolution of legal systems to address the issues it raises
- the limitations of current mental capacity legislation and some of the steps being taken to improve its scope and operation
- the relationship between mental capacity and mental health legislation
- current levels of knowledge and engagement with mental capacity legislation by service users, carers and professionals and measures to improve uptake of what the legislation offers
- issues surrounding the assessment of mental capacity and the need for awareness raising and training of professionals to improve the process and outcomes of assessment

Introduction

Decision-making is an integral aspect of everyday life. We make decisions about all kinds of things such as what to wear, what to eat and whom to socialise with, quite naturally and usually (but not always!) without effort or difficulty. On the other hand, there are more important decisions such as choosing a partner, accepting a particular medical treatment or buying a house that may take more reflection and research to accomplish. Like many human capabilities, most of us take decision-making ability in ourselves, and those around us, for granted. This makes it all the more difficult to deal with when things go wrong as a result of stressful or traumatic life events, or physical or mental illness or injury. When this happens, a person may struggle to participate in

decision-making and, in some cases, may not be able to participate at all. When a person cannot make decisions independently, she is said to have impaired mental capacity. This becomes particularly important when someone is facing a decision that must be made. For example, he may be in the process of being discharged from hospital and need to decide whether to go back home or into supported accommodation. Alternatively, he may have a serious illness requiring urgent medical treatment. Crucially, impaired mental capacity prevents a person from giving 'informed consent' regarding what happens to her and, therefore, restricting her right to self-determination and autonomy. Informed consent is a legal requirement before professionals can perform health or social care assessments, make interventions, or take action about placement, living arrangements or financial matters. Due to this, special legislation is required to protect those who lack capacity and those who act on their behalf without informed consent. Generally, such legislation can make four kinds of provisions:

- a person can make decisions in advance (advance decisions/directives) about refusing treatments - but not about deciding which treatment he wants
- he can appoint someone in advance to make decisions for him (powers of attorney)
- professionals can make decisions on his behalf - often, but not in all cases, based on the principle of 'best interests'
- a court can appoint someone (a Deputy) to make decisions on behalf of the affected person.

Mental capacity is a significant and increasing issue in health and social care. Mental incapacity rates in older adults in long-term care settings ranged from 44% to 69% in a review of studies (Moye and Marson, 2007). In general, non-elective acute hospital inpatients rates of incapacity ranged from 37% to 40% (Etchells et al., 1999; Raymont et al., 2004). However, a lower, but still significant, rate of 26.7% was reported by Fassassi et al. (2009) in a general medical ward in Switzerland. A review of 99 studies of consent to treatment in older people found that age and lower educational standards were commonly associated with impaired ability to consent (Sugarman, McCrory and Hubal, 1998).

Factors that may affect mental capacity

Mental capacity depends on the core abilities of being able to assimilate, remember and process information and to communicate the decision. Any condition or life-event that affects any of these core processes can affect capacity. Some include:

- **Intellectual disabilities**, often present from birth and caused by a range of factors from genes to adverse conditions or events
- **Dementia**, due to its impact on memory and reasoning
- **Brain injury and stroke**, which can affect cognition and communication
- **Mental health problems**, such as psychosis, depression and anxiety, as they can distort the way information is processed to arrive at decisions
- **Delirium** resulting from infections, drugs and intoxicants, which can temporarily affect mental capacity
- **Other causes** that prevents a person from thinking clearly and taking in information, such as severe traumatic events, grief or pain

Box 1: Factors that may affect mental capacity

- health conditions or events that affect perception, thinking, memory or communication
- cognitive abilities
- communication ability
- mood and emotional factors
- support which presents information about the decision intelligibly and helps the person reach and communicate his/her decision
- the nature of the decision to be taken; more complex decisions are more demanding of the abilities underpinning mental capacity

The history of mental capacity legislation in England and Wales

Mental capacity legislation has implications for a significant proportion of the population of all developed countries; probably over 10 percent if the carers of people with impaired decision-making are included. Moreover, the scope of mental capacity

legislation is extremely broad, encompassing financial, health, welfare and social areas.

The social and ethical dilemmas posed by adults who lack the ability to make decisions for themselves have existed since the dawn of human groups and societies, and initially were determined by religious teachings. More recently, formal legal codes have been developed that address mental incapacity in a way that is systematic, open to scrutiny and revision and capable of being administered and enforced by the legal system.

In England and Wales, mental incapacity law dates back to the thirteenth century, when powers to deal with the estates and welfare of people who were incapable of making decisions was given to the king. Subsequently, the Chancellor's office gained powers to appoint a person to control the estates, affairs, health and welfare of those who lacked capacity. These powers lasted until the Mental Health Act 1959 abolished the Chancellor's powers over health and welfare. However, powers over health and welfare were subsequently reintroduced into the Mental Capacity Act 2005 (MCA) for England and Wales.

Limitations to mental capacity legislation

In 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities and this has since been ratified by the UK. This has the core purpose *“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”*. The convention states that treatment of disabled people (including those who lack mental capacity) should:

- respect inherent dignity, individual autonomy and independence of all people, including the freedom to make their own choices,
- be non-discriminatory
- allow full and effective participation and inclusion in society.

The Convention emphasises that *legal capacity* (the ability to hold rights and duties and to exercise these rights and duties) is a universal right that applies even for those without *mental capacity*. Therefore, it is important that mental capacity legislation

does nothing to diminish legal capacity. In this respect, substitute decision-making by a healthcare practitioner or someone with powers of attorney using the principle of '*best interests*' can be seen as discriminatory. The United Nations Convention on Human Rights prioritises supporting the person in making her own decision and highlights the primacy of the wishes and preferences of the person without capacity. The notion of a '*best interests*' outcome, as judged by a substitute decision-maker, has no place in this formulation. It is true that mental capacity legislation requires that a person should be supported to participate in decision-making and that his past wishes and preferences should be considered, but the United Nations Convention views the wishes of the person as paramount, rather than a third party's evaluation of '*best interests*'. In the British Isles, the mental capacity legislation of Scotland (2000) and the Republic of Ireland (2015) do not use the idea of best interests, but instead emphasise supporting a person to participate in decision-making and determining what she would want based on her principles, values and past history. (See chapter 2 for further discussion of this topic).

Impaired mental capacity also evokes the crucial question of when (or if) a person's wishes should be overruled in order to protect him from harm or exploitation. For example, Section 4 of the MCA (2005) for England and Wales makes provision for the overruling of a person's wishes and the use of restraint if this protects her from harm, but neither the Act nor the Code of Practice (2007) are able to provide definitive guidance about the criteria for overruling a person's right to autonomous choice other than the general principle of preventing harm to the person. However, this has been refined by case law over several years; for example, emotional wellbeing, and not just physical wellbeing, must be taken into account when assessing 'harm' to the person.

Closely linked to this debate is the need to restrict a person's freedom of movement (to deprive him of his liberty) in order to safeguard him from harm. For example, a person with a severe intellectual impairment who will not remain in a residence but is at risk of serious accidents when out unsupervised may need to be placed in a secure, locked facility. Such deprivation of liberty could be viewed as contrary to a person's basic human right to liberty, especially if it is long-term. In England and Wales, two amendments have introduced new authorisations and periodic review processes for people deprived of their liberty under the MCA (2005) – the Deprivation of Liberty

Safeguards (Mental Health Act, 2007) and the Liberty Protection Safeguards (Mental Capacity (Amendment) Act, 2019). (See chapter X for further discussion of this topic.)

A further criticism of the MCA (2005) is that its scope is too limited; it applies only to those whose capacity is impaired by a disorder of mind or brain but there may be other reasons for impaired decision-making capacity and the restriction of individual autonomy. These include coercion, undue influence or lack of access to vital information. Consequently, it has been proposed that the requirement for having a disorder of mind or brain be removed and that the definition of mental incapacity should refer to *any* cause that impedes autonomous decision-making. This would encompass social reasons for impaired decision-making and include people who are under the influence of human traffickers or self-interested family members or who are affected by trauma or adverse life events. The mental capacity legislation of the Republic of Ireland has taken note of this and does not require a person to have an impairment of mind or brain (see chapter 2).

Finally, mental capacity legislation and the associated codes of practice emphasise individual autonomy and rights. The primacy of individual rights is a feature of industrialised western societies, but is less prominent in many African, Middle Eastern and Eastern societies where decision-making may be focused on the family or social unit rather than its individual members. The increasing trend for migration from less wealthy countries, or those divided by conflict, to more developed countries has created multicultural societies which may require greater flexibility in mental capacity legislation to recognise the cultural diversity of approaches to decision-making.

In working with current mental capacity legislation, professionals should be mindful that any legislation is not permanent and infallible (even if it is ‘the law’). Instead, mental capacity legislation is: 1) based on the prevailing system of belief and socio-cultural conventions; 2) liable to change as conventions change. As an example, in recent times mental capacity legislation in England and Wales has been amended every 20 to 30 years (1833, 1862, 1890, 1913, 1934, 1959, 1983, 2005, 2007, 2019). Professionals and professional groups involved in implementing mental capacity legislation, should be mindful of its limitations and proactive in identifying and publicising aspects that require amendment in response to social and cultural change.

Box 2: Limitations to mental capacity legislation summary

- Mental capacity decisions made by someone else based on perceived '*best interests*' are not fully compliant with human rights codes.
- Restricting the freedom of a person without mental capacity is controversial and is subject to special safeguards.
- Decision-making ability may be impaired when there is no disorder of mind or brain. The definition of mental incapacity needs to take this into account.
- The primacy of individual autonomy is not embraced by all cultures.
- Implementation of the Act should respect cultural diversity.
- Mental capacity law depends on the social and cultural context which changes every few decades. Professionals should be mindful of the need for change as it arises.

Mental health legislation and mental capacity legislation

There clearly is substantial overlap between mental health and mental capacity legislation. Both allow for decisions to be made for a person in some circumstances and for a person to be detained when he might come to harm. It is sometimes unclear which type of legislation should be used when a person lacks capacity as a result of mental illness. Since mental health and mental capacity legislation differ there is potential for confusion. Consequently, there have been calls for the two types of legislation to be fused, and this has now happened in Northern Ireland (2016). However, as discussed in Chapter 2, the Northern Ireland legislation is in the early stages of implementation and there may be significant hurdles before it can be used in practice. (See chapter X for a more in-depth discussion of these points.)

Service users' and carers' appreciation of mental capacity and decision-making

User groups, such as the Alzheimer's Society, strongly supported the MCA (2005), and carers and service users with experience of mental capacity in decision-making also welcomed the principles and provisions of the Act (Manthorpe, Rapaport & Stanley, 2009). Unfortunately, there is poor awareness of mental capacity legislation in the general population (Das, Das & Mulle, 2006). Consequently, many people miss opportunities to benefit from Advance Decisions/Directives or appointing people with powers of attorney before losing capacity. A sample of service users and carers (Manthorpe et al., 2009) felt that professionals should publicise the Act, something that is required of health care providers in the United States, and provide service users and carers with specific information about the Act's provisions.

Myron et al. (2008) identified several factors that encourage older people in mental health settings to become involved in decision-making about their treatment: being listened to, having a choice of communication methods (verbal or written), being familiar with and trusting the staff involved and having pleasant environments and positive, 'friendly' staff. Conversely, some factors made participation in decision-making less likely: circumstances that did not build confidence to make decisions, prejudice and the assumption that people with some health conditions were incapable of decision-making. In addition, carers struggled to participate in decision-making when they knew that the person was different from his former self and when they felt accountable for decisions on behalf of another person.

Professionals and mental capacity

A House of Lords report in 2014 concluded that there was poor knowledge of the principles and provisions of the MCA (2005) and that they had not been sufficiently included in the practice of health and social care professionals. This supports the conclusions of research in the British Isles and North America regarding staff knowledge and confidence about mental capacity (Jackson & Warner, 2002; Myron et al., 2008; Schiff et al., 2006; Ganzini et al., 2004; Wilner et al, 2012, 2013; Marshall & Sprung, 2016). Emergency service workers in England had poor knowledge of the basic principles of the MCA (2005); for example, that a competent person who

refuses treatment should not be treated and that a relative's signature is not necessary to treat an incompetent person. In this study 33% of doctors, 90% of nurses and 100% of ambulance workers gave incorrect responses (Evans, Warner & Jackson, 2007).

It has been argued that medical practitioners lack the training and skills required for the complex nature of many capacity judgments (Silberfeld & Checkland, 1999). Myron et al. (2008) found that nearly all the staff in their study wished for more training and guidance on the operation of the Act. However, another study found that some healthcare staff did not subscribe to the principles of shared decision-making and service user autonomy and felt that the approach is unnecessary and impracticable (Gravel, Legare and Graham, 2006).

Manthorpe et al. (2009) noted staff concerns over the resources required to implement and monitor the MCA (2005), and the risks associated with any failings in its implementation. Full assessment of capacity, including consultations with family, friends or Independent Mental Capacity Advocates (IMCA), can be time-consuming. However, taking shortcuts could result in an incorrect outcome about someone's capacity to make a decision. Moreover, there is no provision in the Act to monitor whether decisions are genuinely in a person's best interests.

For people with intellectual impairments in residential care, Dunn, Clare & Holland (2008) demonstrated that important life planning and healthcare decisions for a person did generally follow the model proposed for best interests decisions by the MCA (2005). However, day-to-day decisions, such as choice of clothes or meals, were often taken spontaneously by staff without any attempt to obtain the person's views or to get informed consent. Dunn et al. (2008) recommended that national standards for care should incorporate the provisions of mental capacity legislation and should be applied whenever decisions were required.

On a more positive note, although there is no specific qualification system for the MCA (2005) in England and Wales, as there is for the Mental Health Act (for example, responsible clinician qualification), healthcare providers in the UK have taken steps to improve staff awareness of mental capacity legislation through mandatory training of all relevant staff. However, training must be delivered in an

appropriate manner: Wilner et al. (2013) found only limited benefit for classroom-based MCA (2005) training in learning disabilities settings and recommend that classroom training is combined with actual experience of cases with opportunity for discussion with mentors and supervisors (see chapter 17).

Box 3: Staff and mental capacity summary

- Many staff have poor knowledge about mental capacity legislation and lack confidence in using it.
- The provisions of mental capacity legislation are not routinely applied in health and social care services.
- Most staff welcome training about mental capacity, but some do not agree that services users should be allowed to make their own decisions.
- Staff are worried about the time and resources required to implement mental capacity legislation properly.
- Important decisions often do follow the guidelines of mental capacity legislation, but day to day decisions and routine care often occur without consent or consultation.
- Training about mental capacity is increasing, but it requires practical training as well as classroom sessions.

Assessment of mental capacity in practice

Most hospital staff find capacity assessment difficult and challenging in practice (Jayes, Palmera & Enderby, 2017). Reasons included time pressure, a perceived lack of knowledge or skills, and concerns about poor practice. When making discharge decisions, members of multidisciplinary rehabilitation teams were uncertain about the capacity of around one third of patients on average before a formal assessment had been completed; the uncertainty was most marked for those who were judged to lack capacity on formal assessment (Mackenzie, Lincoln and Newby, 2008).

There is evidence that mental capacity assessment for treatment decisions is not undertaken in the majority of cases where capacity is lacking. For example, an audit of capacity assessments in a general medical setting found only 7.5% of patients received an assessment - much less than the rate of incapacity. Moreover, all these

assessments were when patients disagreed with the medical team about treatment! This suggests many patients who lacked capacity received treatment without consent when they did not object to the clinicians' treatment recommendation (Sleeman & Saunders, 2013). This is supported by other studies, and it is likely that between around 60-70% of patients without capacity are treated without the benefit of an assessment of capacity (Rahman et al., 2012; Raymont et al., 2004; Sessums, Zembrzuska & Jackson, 2011).

Box 4: Problems with assessment of mental capacity summary

- Mental capacity assessment is difficult and challenging in many services.
- Staff are often uncertain about whether a person lacks capacity or not without a formal capacity assessment.
- Many people without capacity who comply with treatments do so without being given a mental capacity assessment.

Agreement in mental capacity assessment

Mental capacity assessment can be complex (Raymont et al., 2007) so it is not surprising that agreement between practitioners is imperfect. Marson et al. (1997) found only near-chance agreement (56%) in the capacity assessments of five physicians for 29 patients with mild Alzheimer's disease. There were large differences in stringency of judgment (90% to 0% judged to lack capacity), and the physicians used different cognitive models in their assessments. Fassassi et al. (2009) found that physicians rarely said someone had capacity when a psychiatrist judged he did not, but frequently said that a person lacked capacity when a psychiatrist said that he did in fact possess it. The agreement with the psychiatric assessment for other members of the healthcare team was even lower. Agreement may be affected by differences between physicians regarding the cognitive functions that are important for capacity. Earnst, Marson and Harrell (2000) found that physicians based their judgments on one or two specific cognitive functions (for example, memory,

communication, orientation to time or place) and that these functions differed between physicians. Agreement rates also depended on the nature of the patient sample (Raymont et al., 2007); the 78.5% agreement between practitioners when assessing 40 acute general medical patients was much higher than the near chance agreement for Alzheimer's patients reported by Marson et al. (1997).

It has also been shown that individual practitioner's assessments lacked agreement with assessments made by multidisciplinary teams. The assessment methods used by different physicians were varied and inconsistent and staff assessments did not agree with standardised assessments (Sullivan, 2004).

On a more positive note, it is likely that many of the issues with mental capacity assessment are due to inadequate or inconsistent training. It has been demonstrated that agreement about capacity assessment depends on staff knowledge and skill and that it improves with training (Marson et al., 2000).

Box 5: Staff agreement in assessing mental capacity summary

- Professionals' agreement about mental capacity is often low.
- This may be due to differences in understanding about what constitutes lack of capacity.
- Training may help to increase agreement.

Summary

In this chapter:

- We have considered how decision-making ability is a vital part of our lives but, sadly, an increasing number of people in society lack this ability at some point in their lives due to physical, mental or social factors. Many, but not all, of these factors are health related. They include brain diseases and injury,

intellectual disabilities, severe mental health conditions as well as traumatic life events and social conditions. Many are not permanent.

- When decision-making is impaired, it may become difficult or even impossible for a person to make vital decisions about her welfare. In such cases she is said to lack mental capacity or decision-making ability.
- The implications of this can be sufficiently serious to require special legislation (mental capacity/incapacity laws) that provide ways of enabling the person's wishes to be fulfilled even when he is unable to fully participate in decision-making.
- However, the issues are complex and embrace current thinking about fundamental human rights and values, especially when the outcome may be restriction of liberty. So, as this thinking evolves nationally and internationally, mental capacity legislation must also evolve to keep pace. We have seen that the countries of the British Isles are recognising the defects of past legislation and are actively engaged in revising their mental capacity Acts.
- People with conditions that are likely to affect their mental capacity welcome legislation to protect them and help them to participate in decisions, but many are disappointed that the helpful provisions of the legislation are not better advertised and applied by professionals.
- Adherence to mental capacity legislation by professionals has historically been poor and has tended to remain so. However, there are signs that organisations and services are offering training that may improve this situation, but the training needs to be practical, with hands on experience, and staff need the time and resources to properly assess people and support them to make decisions.
- Agreement between staff about mental capacity can be low. There are several systems to help with assessment and improve agreement, but they all have limitations and there is a need for more research in this area.
- Perhaps the most promising route to improving assessment and appropriate interventions to support decision-making is to emphasise staff training and improve awareness of mental capacity legislation in professionals and the public. In this way, those with impaired mental capacity can be identified and

helped to benefit from the many methods to support and assist them to participate in decision-making (see chapters X and Y).

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