

OPINION PIECE

Overview of the Assisted Decision-Making (Capacity) Act (2015)

Implications and opportunities for occupational therapy

Ruth Usher

University of Dublin Trinity College, Dublin, Ireland, and

Tadhg Stapleton

*Trinity Centre for Health Sciences, University of Dublin Trinity College,
St. James Hospital, Dublin, Ireland*

Abstract

Purpose – In Ireland, the Assisted Decision Making (Capacity) Act 2015 provides a statutory framework to adults who are experiencing difficulties with decision-making. This legislation has significant implications for all who work in health and social care. Increasing age and life expectancy, alongside the rising incidence of chronic health conditions and dementia-related diseases, indicates that more individuals are likely to experience challenges regarding decision-making capacity. Therefore, the need for more consistent, best-practice processes to assess decision-making capacity is likely to increase. To ensure occupational therapists are responsible in their contributions, and to ensure those with disabilities are supported, clinicians must be well-informed of the principles underscoring the Act. The purpose of this paper is to provide an overview of this multidisciplinary issue, including recent legislation, and consider how occupational therapy can contribute.

Design/methodology/approach – The authors reviewed current literature and considered occupational therapy's role in decision-making capacity assessment.

Findings – Occupational therapists have potential to play a key role in multi-disciplinary assessments of decision-making capacity for clients. Further research is required to explore professional issues, identify clinical best practices and determine training and resource needs.

Originality/value – This paper seeks to provoke consideration of how occupational therapists can contribute to capacity assessment from a client-centred, occupation-based perspective that is mindful of ethical and legislative considerations.

Keywords Risk, Occupational Therapy, Capacity, Decision-making, Cognitive assessment, Client-centred practice

Paper type Viewpoint



Introduction

In most democratic countries, there is a basic assumption that adults have the right and capacity to make decisions around issues affecting their lives, such as where to live, social engagement choices, personal care preferences, financial decisions and healthcare decisions, based on the premise that adults have adequate understanding, appreciation, reasoning and choice (Wong *et al.*, 1999; Charland, 2015). When there is concern about the decision-making capacity (DMC), an ethical dilemma may arise between two core principles of respect for autonomy (self-determination) and need for protection from harm (beneficence) (Aldous *et al.*, 2014; Wong *et al.*, 1999).

The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) has stimulated significant debate about decision-making rights of people with disabilities. Article 12 states as a basic principle that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (p. 9). This reflects growing recognition of individuals as experts in their own lives and the inherent human rights of all individuals to participate in making decisions in all aspects of their lives (Knox *et al.*, 2013).

Capacity is a legal, clinical, ethical and social construct (Hotopf, 2005), requiring knowledge of bio-psycho-social factors, ethics and the law (Moye and Marson, 2007). The issue of DMC is increasingly being recognised as a significant concern to society and healthcare systems (Moye and Marson, 2007; Parmar *et al.*, 2015), particularly among people with cognitive impairments. Owing to concerns around risk, safety and well-being, determining DMC and supporting people with cognitive disability to participate in decision-making is considered one of the most conceptually and ethically challenging areas of clinical practice (Banner, 2012; Bigby *et al.*, 2017a; Parmar *et al.*, 2015).

All healthcare and social care professionals (HSCPs), including occupational therapists, are ethically and legally obliged to be aware of new developments and legislation regarding DMC, particularly when working with clients with cognitive disability, such as those with intellectual disabilities, mental health difficulties or neurodegenerative conditions, such as dementia. The Code of Professional Conduct and Ethics set out by the HSCPs regulator, CORU, specifically states occupational therapists’ responsibility to “support the service user’s right to take part in all aspects of the service provided and to make informed choices about the service they receive” (Occupational Therapists Registration Board (OTRB), 2014, p. 7).

Numerous challenges with DMC assessment have been described in the literature, such as time pressures; HSCPs having differing interpretations of capacity; lack of knowledge about capacity assessment; tendency to rely on standardised tests which are not designed for capacity assessment; and practices that are not consistent with legal requirements (Jayes *et al.*, 2017; Lamont *et al.*, 2017; Parmar *et al.*, 2015). Occupational therapists in Ireland may experience similar challenges. Therefore, additional support and resources to aid practice in DMC assessment and support may be of benefit.

Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act was signed into law in 2015 (Department of Justice and Equality, 2015). A presumption of capacity underpins the new Act. It recognises and maximises the rights of all adults, regardless of age, disability or diagnosis, to make decisions about their personal welfare, property and affairs, regardless of age, disability or diagnosis, with legally recognised supports. It repeals Ireland’s existing capacity legislation, the Lunacy Regulations (Ireland) Act 1871, which utilised a status approach to capacity, equating certain disability or impairments with loss of legal capacity and has been criticised for being overly protective and discriminatory (National Safeguarding Committee, 2017).

Scope of the Act

The provisions of the Act apply to decisions and interventions related to healthcare and social care in hospital, residential and community settings. It includes day-to-day decisions, such as personal care preferences, and more complex decisions such as those regarding finances, where to live and consent to treatment. The Act places an obligation on all HSCPs to support a person to make their own decisions as far as possible, and where the person's capacity is in question, to provide all practicable support to facilitate the person to make the particular decision. All HSCPs, including occupational therapists, working with persons who require assistance in exercising their DMC should be familiar with the Act and consider its implications for practice.

Commencement

Since October 2016, the Act has partially commenced, allowing the establishment of the Decision Support Service (DSS) and the drafting of codes of practice by HSE and the National Disability Authority, underway at the time of writing. While there is general awareness of the new Act, it is unclear when it will be fully commenced and some concerns have been raised about how it will work in practice (Kelly, 2017; National Safeguarding Committee, 2017). Through the HSE Assisted Decision-Making Steering Group, HSCPs, including occupational therapists, had opportunity to engage in consultation on the HSE draft guidance papers regarding practice guidelines on DMC assessment and advanced care planning (HSE, 2017; HSE, 2018). However, Ratcliff and Chapman (2016) observed that in the UK, comprehensive training around their capacity legislation did not necessarily lead to high-quality application of requirements in practice, due to knowledge gaps among HSCPs. Therefore, it is imperative for occupational therapists to be aware of the Act, to understand issues related to DMC assessment and to consider our potential role in contributing to this process (Figure 1).

Functional approach to DMC assessment

Section 3 of the Act sets out a functional approach to DMC assessment: The person's DMC must be assessed on the basis of their ability to understand the nature and consequence of the decision at the time of decision-making. DMC is therefore an ongoing and fluctuating process that is time-, issue- and context-specific (HSE, 2017, 2018).

The Act sets out a number of guiding principles as outlined in Guiding Principles of Assisted Decision-Making (Capacity) Act (2015), Section 8:

- (1) A person is presumed to have capacity in respect of the matter concerned unless the contrary is shown.
- (2) A person shall not be considered as unable to make a decision unless all practicable steps have been taken to help him or her do so.
- (3) A person shall not be considered as unable to make a decision merely because the decision made or likely to be made is an unwise decision.
- (4) Intervention should only take place on the basis of necessity and individual circumstances.
- (5) Intervention must be made in accordance with human rights, be proportionate and limited in duration.
- (6) The intervenor must make maximum efforts to meet the wishes of that individual and take account of other specified requirements and interests

While capacity assessment is deemed a legal rather than a healthcare issue, HSCPs need to be aware of the legal context and policy matters (Darzins, 2010). Assessment of capacity is

What you need to know about the
Assisted-Decision Making (Capacity) Act 2015



Source: Oireachtas Library and Research Service (2017), reproduced with permission

Figure 1.
 Overview of the
 Assisted Decision-
 Making Capacity Act
 (2015)

in fact part of every clinical situation because it guides both interaction and subsequent management (Bastian *et al.*, 2011).

Supported decision-making

Recognising that a person with cognitive difficulties may be able to exercise legal agency, if they are given adequate support to express their wishes and preferences, requires DMC assessments go beyond identifying a person’s decision-making impairments, to identify the necessary support required to exercise legal capacity. Therefore, HSCPs must develop understanding of their roles, to ensure that individuals are given the support and accommodations that they require to maximise their participation in decision-making about their lives.

Moye and Marson (2007) identified at least eight categories of DMC requiring assessment among older adults: independent living, financial management, driving, consent to treatment, sexual consent, research consent, voting and testamentary consent. Various HSCPs will have involvement in DMC across these domains, according to their typical practice areas.

In the event of a person who is unable to independently make a decision in the above domains, the Act sets out a framework of decision-support arrangements, with different levels of support from third-parties. The core of supported decision-making is that people

with cognitive disability have access to assistance for decision-making to enable participation in society on an equal basis. The concept has developed in Canada, Australia and Sweden. A supported decision-making approach that places onus on the amount and quality of support available to help people make decisions, rather than their cognitive abilities, recognises the nature of human interdependence, regardless of cognitive ability (Watson, 2016). The Act outlines the role of:

- decision-making assistant;
- co-decision-maker; and
- decision-making representatives.

The Act also sets out procedures for advanced healthcare directives and enduring powers of attorney for individuals with diminished DMC, and are described elsewhere (HSE, 2017; HSE, 2018; Kelly, 2017) (Figure 2).

The issue of how decision-making support is delivered in practice, in terms of quality and effectiveness, will require on-going attention as this Act is commenced. Donnelly *et al.* (2018) investigated social workers practice in Ireland in supporting people with dementia’s involvement in decision-making and reported cultural, organisational and professional barriers to fully implementing the Act, such as lack of standardised practices and lack of awareness among HSCPs of their obligation to facilitate and support decision-making. Much work is required to discover how supported decision-making is best implemented, how to meaningfully and accurately discover an individual’s will and preference and how that process can become part of service provision to ensure it truly fosters autonomy and well-being (Arstein-Kerslake *et al.*, 2017).

Decision-making

To date, the substantial focus of the literature and practice relating to decision-making has focused on cognitive aspects, such as identifying and describing the nature of deficits in decision-making. More recently, research and debate has highlighted that an individual’s values and prior life experience need to be taken into account when considering cognitive and emotional processes for DMC assessment (Knox *et al.*, 2013).

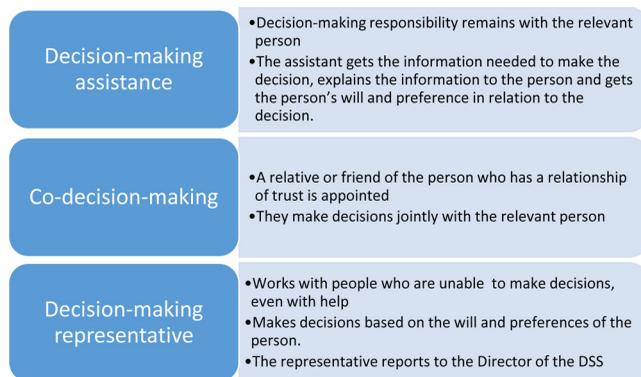


Figure 2.
Decision-making supports by DSS

Source: Adapted from Oireachtas Library and Research Service (2017)

To ensure decisions align with personal goals and values, individuals must be supported to make decisions for themselves. For individuals with a disability, the opportunity to exercise choice and making decisions about one's own life is important for personal well-being and sense of identity (Bigby *et al.*, 2017a; Brown and Brown, 2009; Nota *et al.*, 2007).

Respecting and responding to the needs and preferences of clients and empowering them to make decisions to meet their needs is considered fundamental to high-quality, client-centred practice (Jayes *et al.*, 2017; Stojan *et al.*, 2016), as specified in the Association of Occupational Therapists in Ireland (AOTI) Code of Ethics and Professional Conduct (AOTI, 2013, p. 4):

A member must ensure that the client has received all of the relevant information to allow the client or his/her representative to make informed choices or decisions about likely benefits and risks of the occupational therapy intervention options and to safeguard his/her dignity.

Given the concept of decisional capacity is based on the concept of informed consent, which intends to promote and protect the autonomy of healthcare subjects (Bigby *et al.*, 2017b), it is prudent to review the HSE National Consent Policy (2014, 2017) which is clear in its requirement for HCPs to use a “functional” approach and that cognitive deficits are only relevant if they actually impact on decision-making. Similar to the Act, the guidelines emphasise our duty to maximise capacity, the presumption of capacity, and that “even in the presence of incapacity, the expressed view of the service user carries great weight” (p. 33). However, Donnelly *et al.* (2018) found little evidence that a functional approach to DMC assessment is employed in Irish practice and suggested a collective effort is required to ensure the Act informs practice in a meaningful way.

Occupational therapists' involvement in DMC assessment

Occupational therapists commonly receive referrals to conduct assessments to assist in determining the DMC of individuals to make decisions. Of the eight areas identified by Moye and Marson (2007), it's likely occupational therapists have definite involvement in at least four of these: consent to treatment, driving, financial management and independent living. Occupational therapists can make important contributions to decisions about individual's abilities to live independently (Darzins, 2010). McNally (2016) explored DMC assessment practice of occupational therapists in acute hospitals regarding independent living for older adults and found occupational therapists tended to utilise standardised and non-standardised assessments to evaluate cognitive ability and functional performance. While many different assessment methods are used by occupational therapists, no guidelines exist regarding the most thorough way to approach these DMC assessments to ensure client-centred, occupation-based practice.

Current issues

Assessment approaches

Until recently, DMC capacity was often understood as a broad-based cognitive ability and cognitive assessment remains one of the most prominent practice issues. The focus on individualised cognitive skills, rather than environmental barriers to self-determination, is in direct conflict with the social model of disability, which is embedded within UNCRPD (Watson, 2016) and also the Act. The denial of legal capacity on the basis of cognition adds to prejudice against people with cognitive disability, reaffirming discriminatory notions that they cannot be full and valuable members of society (Arstein-Kerslake *et al.*, 2017; Flynn and Arstein-Kerslake, 2014).

The HSE's draft guidelines (2017) in relation to the implementation of the Act clearly asserts that “Cognitive tests (such as the Mini-Mental State Examination (MMSE) or the Montreal Cognitive Assessment (MOCA)) . . . do not determine and should not be used for

assessing a person's decision-making capacity" (p. 47). Furthermore, it warns their use is inconsistent with the presumption of capacity and the functional approach to capacity. This requires occupational therapists to examine their role and contribution to DMC and echoes previous critique of general occupational therapy assessment, which focuses primarily on disabilities, dysfunction and deficits rather than on abilities, strengths and resources (Hammell, 2015).

The dominance of the medical model in settings where many occupational therapists work leads to focus on impairment, with little explicit concern for occupational performance and engagement needs of clients (Kielhofner, 2009; Molineaux, 2011; Wilding and Whiteford, 2007). Stigen *et al.* (2018) describe a "conflicted practice" whereby occupational therapists use impairment-based standardised assessments for efficiency and on request of colleagues, despite valuing occupation-based approaches. Focus on only cognitive assessment components rather than occupational performance could be viewed to demonstrate incongruence with the profession's philosophical basis and espoused commitment to client-centred practice. Adopting a strengths-based approach, appreciating abilities and enhancing resources is congruent with client-centred practice and empowerment and also with the Act's approach to supporting decision-making.

Bright *et al.* (2012, p. 1002) challenges occupational therapists to change their focus from assessing "What is wrong with this person and what can I do for them?" to asking "Who is this person and what do they need?" Hammell (2016) urges occupational therapists to firstly understand people's assets and choices in order to help them enhance their capabilities. Adopting this approach is in line with the DMC assessment which should focus on the support that is needed in decision-making to enhance an individual's existing strengths, rather than individual deficits (Flynn and Arstein-Kerslake, 2014).

The goal of a well-crafted capacity assessment is to elucidate the degree of "person-environment fit" (Grisso, 1986 cited in Capacity Assessment Office, 2005). Similarly, occupational therapy models, such as the PEO model (Law *et al.*, 1996), provide frameworks that guide clinical reasoning in analysis and understanding of the interaction between the person, the environment and the occupation. Occupational therapists can assess an individual's physical and cognitive abilities alongside the impact of the social, cultural and physical environment. The ability of a person to participate in meaningful activities within the context of their environment is indicative of their level of functioning and disability (Lesher *et al.*, 2017). In terms of independent living, this may be more informative than a score from a standardised cognitive assessment.

The Occupational Therapy Practice Framework (OTPF) (AOTA, 2014) may be a useful framework to consider the role and functions of occupational therapy in assessment of DMC. The OTPF identifies performance *skills*, performance *patterns* and activity *demands* as assessment components to analyse an individual's functional needs and performance difficulties, emphasising that it is not only the individual's body structures and functions that determine ability, but also the environment and characteristics of the activity or role itself.

The OTPF includes value and beliefs as important client factors and recognizes that cultural and temporal contexts and the social environment influence participation, similar to the Act which places emphasis on the "beliefs and values of the relevant person". Additionally, core concepts of client-centred occupational therapy emphasise respect for a client's values, beliefs, experience and contexts that influence participation and active collaboration throughout the process, which complements the approach set out in the Act. Therefore, occupational therapy may be well-positioned to contribute to DMC assessment.

The Canadian Model of Client-Centred Enablement (CMCE) is a theoretical model which depicts the client-therapist relationship, based on principles of client choice, risk and responsibility; client participation; occupational justice and power-sharing (Townsend and

Polatajko, 2007). It reminds us that clients have the right to make choices and to live with the risks associated with these decisions (Tam-Seto and Versnel, 2015). Enablement skills, such as advocating, collaborating, consulting, coordinating, educating and engaging (Townsend and Polatajko, 2007), used by occupational therapists to enable occupation, could also be used to support decision-making with clients.

Dignity of risk

Predominant discourse regarding DMC focuses on negative conceptions of risk identification and elimination, rather than approaches which enable individual choice (Knox *et al.*, 2013). Many practitioners favour beneficence over respect for autonomy (Darzins, 2010). Therefore, attribution of positive value to risk-taking and allowing people exercise choice may challenge health and social care institutions with a tendency towards risk-aversion (Gooding, 2013).

Concepts of risk, capacity and levels of insight have also been discussed as potential barriers to client-centred occupational therapy practice, and therefore, occupational justice (Sumison, 2006). McIntyre (2013) urges occupational therapists to move away from being risk managers to risk activators or enablers to maintain the rights, autonomy and dignity of their clients. Wilcock (2005) questioned the general acceptance that risk management is necessary and admirable, as it encourages restrictive, disempowering strategies. Lack of choice and opportunity to engage in valued and fulfilling occupations may be considered an infringement of occupational rights (Hammell and Iwama, 2012) with detrimental consequences for well-being and overall quality of life, a risk in itself. Therefore, occupational therapy practice must be consistent with our professional philosophy, the UN CRPD, and the Act to ensure our clients have the right to full participation in decision-making and equitable access to occupational opportunity.

Conclusion

Approaches to DMC assessment and ways to support decision-making are becoming increasingly critical (Moye and Marson, 2007). HSCPs have an ethical duty to ensure that judgements of capacity are unbiased and accurate (McCormick *et al.*, 2017). Research is required to investigate current occupational therapy practice in Ireland, to explore professional issues and to identify training and resource needs for professionals involved in capacity assessment. Unless it is given thorough consideration, the implementation of the Act may not serve people as intended, and the contribution of occupational therapy to this population may not be realised. As a profession trained in evaluating the occupational strengths and needs of clients, the contexts and environments in which occupations occur, and clients' personal and social factors, occupational therapy has an opportunity to contribute greatly in this area. We have expertise to share with other HSCPs, researchers and policymakers. Occupational therapy should disseminate our insights of occupational performance in areas relevant to DMC assessment, contribute to the research agenda, and ensure our competence in client-centred practice, aligned with the priorities of legislative and health reform. Occupational therapy needs to be part of the discussion around implementing and scrutinising the Act, not only to prove the profession's worth in an evolving system but also for the benefit of our clients.

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Corresponding author

Ruth Usher can be contacted at: usherru@tcd.ie

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