Supported decision making: the rights of people with dementia


Abstract

The Mental Capacity Act 2005 is used to assess a person’s decision-making ability and to make a best interests decision where the individual lacks the capacity to do so. The act was considered to have the potential to maximise the autonomy of individuals with mental or cognitive impairments, but this has not been fully realised. Since the act came into force, the United Nations Convention on the Rights of Persons with Disabilities has challenged many of the principles underpinning the act. That challenge and how existing provisions in the act can be implemented to increase autonomy and control for people with cognitive or mental impairments are discussed. The principles of the convention are described and potential future amendments to the law are identified.

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THE INCIDENCE OF dementia is rising as people live longer. An estimated 850,000 people in the UK are living with dementia, and this number is expected to rise to one million over the next decade (Alzheimer’s Research UK 2015). The World Health Organization (2012) estimated that by 2025, 37 million people globally will be living with dementia.

According to Bartlett and O’Connor (2007), the language and attitudes associated with dementia are changing in response to the wider disability rights movement (Oliver 1990, Campbell and Oliver 1996, Shakespeare 2006, Oliver and Barnes 2012). There has been a shift from a medicalised view of dementia towards a social understanding of dementia, with less focus on the ‘suffering’ of the person. This focus on suffering has ‘silenced people with dementia’ and removed their voice in society (Bartlett and O’Connor 2007). This shift signals increasing recognition of adults with dementia as both people and citizens with rights and voices worth hearing (Bartlett and O’Connor 2007).

The challenge for people with dementia is to be seen as people and active citizens with both rights and a claim to autonomy (Lewis 2006, Bartlett and O’Connor 2007, Boyle 2008, Harding 2012). The Mental Capacity Act 2005 provides scope for increased rights and autonomy for people with cognitive or mental impairments, including dementia (Boyle 2008, Williams et al 2008). The act provides a test for capacity based only on the functional ability of the individual to make a decision. This assessment of capacity should be ‘value free’. In other words, autonomous decisions may objectively be considered unwise, but individuals with capacity have the right to make these decisions.

The act is decision-specific, aiming to remove overarching assumptions of inability to make decisions once dementia has been diagnosed. However, the act has not fully realised this aim. Empirical research suggests that people with mental impairments are subject to paternalistic decision making based on the individual’s diagnosis rather than their decision-making ability (Livingston et al 2010, Williams et al 2012, Emmett et al 2013).
Since the act came into force, there has been a shift from the objective assessment of capacity, to an increasingly rights-based framework under the United Nations (UN) Convention on the Rights of Persons with Disabilities. In particular, article 12 of the convention refers to equal recognition before the law (Secretariat for the Convention on the Rights of Persons with Disabilities 2006).

It is common for UN member states to operate some form of ‘substitute decision-making’ framework in their national laws. These frameworks function in a variety of ways. However, common to all is that an individual with a mental impairment can be declared to lack capacity to make a decision (or all decisions) and the decision (or all decisions) is made on their behalf. These decisions are usually made on an objective basis and are not dictated by the individual’s wishes and preferences. Article 12 of the convention (Box 1) challenges this assumption, placing the individual’s will and preferences at the forefront of the decision-making process.

The act operates a form of substitute decision making in the best interests assessment under section 4. Article 12 of the convention appears to signal an end to substitute decision-making frameworks, at least in their current form. This has the potential to reinforce the rights of people with dementia, since their ability to make decisions is frequently impaired, and also has implications for practitioners working with these individuals.

This article discusses the main principles of article 12 of the convention in relation to clinical practice and the rights of people with dementia.

**Supported decision making and article 12 of the convention**

Article 12 of the UN Convention on the Rights of Persons with Disabilities is the right to equal recognition before the law (Box 1). This means that all individuals, regardless of impairment, must be treated equally by law and recognised as legal subjects. Article 12(2) states that people with disabilities should ‘enjoy legal capacity on an equal basis with others’, thus distinguishing between mental capacity and legal capacity.

Mental capacity is an individual’s ability to make decisions, while legal capacity is a legal status, whereby an individual’s decision is legally recognised and given legal effect (McSherry 2012). The distinction between mental capacity and legal capacity represents a major shift in the design of the majority of legal systems globally, where legal capacity and mental capacity are conflated, and mental capacity is the prerequisite for legal recognition of decisions and actions (Dhanda 2007).

Under the Mental Capacity Act 2005, legal capacity and mental capacity are conflated. For an individual’s decisions to have legal weight, they must be found to have capacity under sections 2 and 3 of the act. The individual’s functional decision-making ability is assessed under these sections. If a person is found to lack capacity to make a decision, the decision is made for them under section 4 of the act, through an assessment of their best interests. The person undertaking the capacity assessment and making the best interests decision must explore and consider the individual’s past and present wishes and feelings. They must also take into account any values or beliefs the person may have, although these are not necessarily determinative. A decision may be taken against the individual’s wishes if those wishes are not considered to be in the person’s best interests.

Article 12 of the convention challenges this position, stating that all individuals have legal capacity, regardless of mental ability. Article 12(3) sets out that the focus of those states which have signed and ratified the convention and are thus bound by its terms, must be to provide support for individuals to exercise their legal capacity and for their will and preferences to be given legal effect. This is in contrast with declaring individuals incompetent and making decisions on their behalf, potentially paying little attention to their will and preferences.

The support required to exercise legal capacity under article 12(3) of the convention is frequently called ‘supported decision-making’ (Devi et al 2011, Kohn et al 2013, Committee on the Rights of Persons with Disabilities 2014). However, the term may no longer be appropriate since there is increasing recognition that support for legal capacity involves more than the support required to make a decision. It also encompasses the support required to give effect to the individual’s current and previously expressed will and preferences (Gooding 2015, Series 2015).

**BOX 1**

**Article 12(1-3) of the United Nations Convention on the Rights of Persons with Disabilities**

Article 12 – Equal recognition before the law
1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

(Secretariat for the Convention on the Rights of Persons with Disabilities 2006)
This shift towards a support framework has led to debate around the implications of article 12 of the convention for traditional substitute decision-making frameworks. It has been suggested that article 12 is unclear and that there is potential to maintain substitute decision making (Bartlett 2012). It has also been suggested that it could be unethical to remove substitute decision making (Richardson 2013). However, over the past few years, there has been increasing consensus that substitute decision making, at least in its current form, is incompatible with the convention (Gooding 2013, 2015, Flynn and Arstein-Kerslake 2014, Arstein-Kerslake 2016). It has been argued that article 12 underpins the convention and, without legal force behind the decisions made by people with disabilities, all the other rights of these individuals in the convention become meaningless (Dhanda 2007, Quinn 2010).

In its current form, the will and preferences of the individual can be incidental to the final decision. This was confirmed by a statement from the Committee on the Rights of Persons with Disabilities (2014), which issued a general comment in response to requests for clarification on interpretation of article 12:

‘States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives.’

Therefore, article 12 implies a move away from the substitute decision-making paradigm to one that is based on supported decision making.

Support for the exercise of legal capacity in practice

The Committee on the Rights of Persons with Disabilities (2014) provided an outline of what constitutes support (Box 2). In the committee’s view, support is a broad term that encompasses formal (legally appointed persons) and informal (peer support relationships) support arrangements. Support includes measures relating to (Committee on the Rights of Persons with Disabilities 2014):

‘…universal design and accessibility – for example, requiring private and public actors, such as banks and financial institutions, to provide information in an understandable format or to provide professional sign language interpretation – in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions.’

Article 12 of the UN Convention on the Rights of Persons with Disabilities challenges our understanding of what it means to make a decision. To be legally valid, existing frameworks, including the Mental Capacity Act 2005, require decisions to be made in accordance with a particular, predefined standard. In the case of the act, this is covered and assessed in section 3. Article 12 of the convention is broadening that scope to include the will and preferences of people who do not meet the required standard of cognitive ability. It is not only about making a decision in accordance with a predefined standard, but also involves working closely with individuals to understand their will and preferences and to determine what they want to happen.

Involving others who know the individual well and understand their communication methods is central to article 12 of the convention. Some individuals require low levels of support, for example information in accessible formats or the use of pictures or Makaton symbols or signs, and are able to make decisions for themselves. However, people with severe impairments, for example as a result of advanced dementia, may have significant difficulty interpreting information and communicating with others. These individuals may be unable to speak and may communicate only through actions. In such cases, people who know the individual well may be able to interpret certain actions and help to determine what the individual wants or does not want to happen.

Gooding (2015) suggested that the term supported decision-making is unhelpful, because it implies that everyone must be supported to make decisions for themselves. There has also been debate about, and opposition to, supported decision making. This is because people may be averse to the idea that individuals with severe cognitive impairments, who may have no verbal

BOX 2

Suggested methods for support of legal capacity

- The individual may choose one person to assist them with certain decisions.
- Peer support, advocacy or other assistance with communication.
- Public and private actors to provide information in an understandable format or to provide professional sign language interpretation.
- Diverse, non-conventional communication methods to assist with the expression of the individual’s will and preferences.
- Advance care planning.

(Adapted from the Committee on the Rights of Persons with Disabilities 2014)
communication ability, can make decisions regarding complex issues (Gooding 2015).

Gooding (2015) stated there is a broad obligation under article 12(3) of the convention to provide support for the exercise of legal capacity. It was also stated that the contrast often made between supported and substitute decision making is conceptually misleading, since it suggests that a decision can never be made for someone. Rather, Gooding (2015) suggested that the Committee on the Rights of Persons with Disabilities: ‘invites States Parties to rethink how decisions are “made for” people in exceptional circumstances, such as where will and preference are unclear or unknown’.

Support of legal capacity involves giving as much support to individuals as possible to enable them to make decisions. Where this is not possible, support should be given to ensure that an individual’s will and preferences are the guiding principles for any decisions made by others. In their consideration of how the Convention could be implemented in Canada, Bach and Kerzner (2010) identified three decision-making statuses.

The first is the legally independent decision-making status. An individual in this category would be capable of independent reasoning, but may require additional assistance. The individual may be assisted to understand information relevant to making a decision and/or to appreciate the potential consequences of a decision. However, the individual ‘makes the decision exclusive of any other formal representations by others acting in a support role’ (Bach and Kerzner 2010).

The second is the supported decision-making status. This refers to individuals who are likely to have difficulty in understanding information or communicating a decision in a way that others, who do not know the individual, can understand. These individuals will require support to communicate their will and preferences to others.

Supported decision making is not intended to be a system of guardianship, where appointed representatives often pay little, if any, attention to the wishes and will of the individual. This decision-making status is based on the close relationship between the individual and their representative, whom the individual has chosen where possible. It relies on interpretation by the representative of the individual’s will and preferences, based on their relationship and close understanding (Bach and Kerzner 2010).

The third is the facilitated decision-making status. This refers to individuals for whom it is not possible to determine their will and preferences, or who have no other people in their lives who have personal knowledge about them and can understand their methods of communication. In such a situation, a facilitator would be appointed to make decisions for the individual. However, priority would be given to the will and preferences previously expressed by the individual and attempts would be made to make the decision that the individual would have made if able to do so.

The model of decision-making statuses proposed by Bach and Kerzner (2010) may appear to be far removed from the existing legal framework under the act. However, there are existing facets in the act that provide scope for increased levels of support in decision making and autonomy for people with dementia.

Increasing autonomy and control for people with mental impairments

The UN Convention on the Rights of Persons with Disabilities is an international treaty, which does not have the same status as domestic law. Although not directly incorporated into UK domestic law, ‘it is recognised and applied by the Strasbourg court and the domestic courts are required by the Human Rights Act 1998 to take account of this jurisprudence’ (Law Commission 2015). Therefore, the convention is influential, but it is not necessarily indicative of immediate legal change.

The UK signed and ratified the treaty and, therefore, agreed with the rights set out in it. The treaty’s influence is evident in the Law Commission’s (2015) consultation on mental capacity and deprivation of liberty safeguards, which discusses the Convention at length in chapter 3. In chapter 6, a scheme of supportive care is proposed as one of the suggestions for reform of the law.

Even without any reform of the law, the Mental Capacity Act 2005 provides scope for increased autonomy and control for individuals. The act provides a test for capacity in sections 2 and 3, and a process for making a decision in an individual’s best interests in section 4. With regard to the capacity test, the individual must first pass the ‘diagnostic threshold’. This is to determine whether they have an impairment of, or disturbance in, the functioning of the mind or brain. An assessment of the person’s decision-making ability must be undertaken. This includes whether the individual is able to:

- Understand the information relevant to the decision.
- Retain that information long enough to make the decision.
Use and weigh the information in the decision.
Communicate their decision.

There are support mechanisms present in the act that are similar to some of the provisions in Bach and Kerzner's (2010) legally independent decision-making status. When undertaking a capacity assessment, reference should be made to the underlying principles set out in section 1 of the act. Section 1(3) states:

‘…a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.’

In addition, section 3(2) states:

‘…a person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).’

The act’s Code of Practice (Department for Constitutional Affairs 2007) suggests that the focus should be on how practitioners can help people to make decisions for themselves, including:

- Providing information sufficient to make the decision.
- Using appropriate communication methods. This includes non-verbal communication and the use of family and/or advocates who may be able to suggest appropriate communication techniques.
- Making the individual feel at ease.
- Using other people who can help the individual understand the information.

The emphasis is on identifying appropriate communication techniques, appreciating that people have different decision-making processes, adopting individualised approaches to decision making, allowing more time for different kinds of decisions, and recognising the value of close relationships in providing the required support. Although such an approach takes time, it can empower people with mental or cognitive impairments and increase control over their lives (Stevens and Hebblewhite 2014).

The convention envisions a system that goes beyond this level of providing support and, unlike the act, does not retain an objective substitute decision-making framework. However, the best interests framework in section 4 of the act provides increased scope for the individual’s involvement and views than is often the case in practice (Dunn et al 2010, Livingston et al 2010, Williams et al 2012, Emmett et al 2013). When undertaking a best interests assessment, section 4(4) requires the decision maker to make every effort to involve the individual in the process. Under section 4(6), the decision maker must also take into account the individual’s past and present wishes and feelings and any beliefs or values that would have influenced the individual’s decision when they had capacity.

While the individual’s views are only one aspect of a best interests decision, such provisions provide scope for increased involvement of the individual. The individuals voice can be heard, even when they are considered to lack capacity to make decisions for themselves. Section 4(7) of the act also requires the decision maker to consult with family and carers about what is in the individual’s best interests and, in particular, to ascertain the person’s past and present wishes and feelings and any beliefs or values. The convention emphasises the involvement of those who know the individual well to represent the person’s will and preferences. This provision is also made in the act.

Therefore, provisions exist in the act that have the potential to provide increased autonomy for people with dementia (Boyle 2008) and others who lack capacity (Williams et al 2008, Stevens and Hebblewhite 2014). However, empirical studies conducted since the Act came into force have suggested that individuals are not being involved in decisions in this way, particularly with regard to strategic decisions such as moving into residential care (Livingston et al 2010). Studies have also suggested that a diagnosis of dementia can result in decisions made when the individual had capacity being overridden when they are considered risky or unwise (Emmett et al 2013).

The involvement of family and carers in the decision-making process is variable. For example, a study by Williams et al (2012) suggested that family members have a significant role in best interests decision making, with long-term relationships being vital in facilitating communication with the individual who lacks capacity. However, a study by Emmett et al (2014), in the context of hospital discharge, suggested that family members find it difficult to advocate effectively for their relatives.

Unlike the facilitated decision-making status outlined by Bach and Kerzner (2010), the best interests process in the act does not make the individual’s wishes and preferences a determinative factor. However, this does not mean that these wishes and preferences cannot be used as a guide in the best interests decision-making process. In considering supported decision making in the context of mental capacity and absence of liberty
safeguards, the Law Commission (2015) stated that some change is both needed and desirable. The Law Commission (2015) also noted that existing case law indicates that the weight attached to an individual’s views depends on each case.

Following the case of Aintree University Hospitals NHS Foundation Trust v James [2013] (Box 3), the individual must be central to the best interests decision-making process at the very least (Law Commission 2015). While there is consensus on the importance of the individual’s views in the best interests decision-making process, the law should provide clarity as to the weight they should be given (Law Commission 2015).

Dispensing with the principle of best interests is not suggested since that would ‘raise many unresolved issues, and would be highly politically and ethically contentious at this stage’ (Law Commission 2015); it would be a radical reform and needs to be a matter for government. However, the Law Commission (2015) considered that the act should be ‘amended to attach a level of primacy to a person’s wishes and feelings’ as part of the best interests process. The Law Commission’s (2015) consultation paper provides some indication of the type of reforms required to better align the act with the convention, and what measures might be introduced in the future.

Conclusion

Article 12 of the UN Convention on the Rights of Persons with Disabilities challenges perceptions about decision making in people who have traditionally been thought to lack the capacity to make decisions. It broadens the scope for decision making, encouraging consideration of the individual’s will and preferences, and exploring alternative ways of working with people who have impairments to determine their will and preferences. While article 12 could be seen as radical, underused provisions in the Mental Capacity Act 2005 that could potentially facilitate increased autonomy and control for people with dementia, as well as other impairments, should be more widely used.

There needs to be increased focus on supporting individuals to make decisions themselves, and fewer assumptions made about those abilities based on diagnosis and the type of decisions being made. Where people are considered to lack capacity, that does not mean that they are no longer part of the decision-making process. A focus on their wishes and feelings in the best interests decision-making process should be maintained, even if ultimately they are not the determinative factors.

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**References**


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