

# INDIA'S MENTAL HEALTH CARE LAWS ON DEMENTIA: AN OVERVIEW AND ANALYSIS

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## ABSTRACT

The legislation regulating dementia care must be constantly rethought from a human rights perspective to preserve the rights of people with dementia. By analysing the concept of autonomy, this paper attempts to review the Indian mental health care law for people with dementia (Mental Health Care Act, 2017 and RPWD) from a human rights perspective. This study compares vulnerability theory to the capacity perspective as a framework for debate, arguing that policymakers should not take a group-oriented approach. The needs of such individuals are as complex and varied as they are. The implementation of the CRPD in India aims to promote the rights of people with mental illnesses, such as dementia. This article looks at whether India's present frameworks are enough for this strategy and give adequate protection.

**Keywords:** Dementia, Health care, Autonomy, Mental Health, Capacity

## INTRODUCTION

A Lancet analysis estimates that the frequency of dementia patients in India will quadruple by 2050. The report forecasts that by the end of 2022, the total would climb to 11,422,692 from 3,843,118 in 2019.<sup>i</sup> In 2019, it was estimated that dementia would be the seventh leading cause of death globally and one of the most significant causes of impairment and dependency among the elderly, with global costs expected to exceed USD 1 trillion.<sup>ii</sup> With an ageing population, India is experiencing a demographic shift. India's life expectancy has nearly doubled from 36.98 years in 1950-1960 to 69.27 years in 2015-2020.<sup>iii</sup> According to the 2011 census, India's old population numbered 103.9 million people, up from 5.63 million in 1961.<sup>iv</sup> In 2001–2011, decadal growth in the ageing population was 35.5 per cent, compared to only 23.9 per cent in 1951–1961.<sup>v</sup> Existing statistics and fresh and revised estimations of existing and future estimates of dementia prevalence suggest that dementia is now a very substantial public health concern.

Dementia is a clinical disorder marked by the loss of cognitive function, such as memory, judgement, speech, sophisticated motor skills, and other intellectual capacities, resulting in a deterioration in the ability to perform daily tasks independently.<sup>vi</sup> Under the mental health care laws, dementia is viewed through the prism of capacity. Recently, there has been a shift away from the default conclusion that an incapacity finding overrides a person's opinions in all its aspects. Judgments that a person cannot choose can have significant legal implications.<sup>vii</sup> In presenting an overview of the law's reaction to the challenges raised by dementia, this article illustrates the law's approach by highlighting the essential role of capacity, which it also questions. There are several reasons why relying just on decision-making abilities when considering dementia is incorrect. Any strategy based on incapacity, for example, brings together a heterogeneous group of people, identifying them based on a quality that they lack. These persons are classified as extraordinary or 'other' in a legal universe that focuses on the independent, capacious individual. However, not all people with low mental ability are the same. A person with dementia may have a different family environment, life experiences, and prospects than someone with acquired brain injury or intellectual or psychosocial issues.<sup>viii</sup> Failure to recognise these contrasts results in an excessively simplistic framework that obscures the complexities of varied situations. Also, when employed as a point of legal distinction, capacity may be a pretty harsh tool, leaving little room to recognise the individual's personality or address the intricacies of decision-making processes or the particular constraints to which a

person with dementia may be subjected.<sup>ix</sup> This article begins with a description of the applicable legal frameworks in India, as contained in the Mental Health Care Act of 2017 and the Right of Persons with Disabilities Act of 2016. It then describes a changing legal environment, which includes, among other things, a greater focus on human rights and a greater recognition of the will and choices of people with diminished capacity. The study then discusses specific legal problems that occur when using a capacity-based approach in the context of dementia. It describes the challenges doctors experience when determining capacity in dementia patients and the incapacity of capacity-based distinction to address more significant concerns of personhood, agency, and control. The article concludes with the assertion that dementia concerns must be addressed on their terms rather than as a subset of a more considerable capacity/incapacity discussion but concedes that there are helpful insights to be obtained from this debate.

## **INDIAN LEGISLATIVE FRAMEWORKS FOR ADDRESSING DEMENTIA**

Dementia patients in India are subject to one of two legal systems. The Mental Healthcare Act of 2017 (MHCA) outlines procedures for admitting and treating people with mental illnesses. In contrast, the Rights of People with Disabilities Act of 2016 (RPWD) focuses more on defining and reiterating the various rights of people with disabilities and tasks government authorities with ensuring those rights and requiring them to fulfil specific functions their realisation. In addition, many recent Court judgements have attempted to fill the hole left by these two statutes by promoting the rights of individuals with mental disabilities.<sup>x</sup> MHCA has been involved in cases where the Supreme Court of India and High Courts have ruled on matters of public concern. In achieving the MHCA's objectives, the Judiciary played two roles: (i) reliant on the MHCA's provisions to address critical constitutional and human rights issues<sup>xi</sup> and (ii) hold duty-bearers accountable for its implementation at both the state and central levels.<sup>xii</sup> Thus, in India, the law relating to capacity and decision-making encompasses legislative rules as well as judicial decisions. There is, however, a distinct underemphasis on "invisible" disabilities caused by mental illness and dementia, notably in legal decision-making, safeguards, and basic needs facilities.<sup>xiii</sup> The legal approach proves competence and testamentary ability to govern oneself and assets. There is no consideration of the

distinguishing features of dementia diagnosis, a degenerative disorder that affects older adults with multiple health conditions.<sup>xiv</sup> Most MHCA's provisions cover all individuals with a mental illness. No laws specifically address dementia. A person with dementia, however, may qualify for the Act's benefits if the conditions are met. In Section 4 of the Mental Health Care Act (MHCA), memory loss, cognitive limitations, or even the diagnosis of dementia do not automatically indicate incapacity and emphasise the importance of establishing the capacity to make decisions.<sup>xv</sup> According to MHCA regulations, the patient's choices and desires regarding treatment decisions are given priority if the patient can do so.<sup>xvi</sup> Patients without capacity may be represented by appointive representatives who interpret their wishes and choices. However, due to the difficulty of diagnosing dementia, determining individual capabilities can be difficult.<sup>xvii</sup> Conventional diagnostic criteria must be used in conjunction with examination for reversible reasons. Since dementia is a diagnosis with legal implications, it must be supported by clinical symptoms and associated investigations. Additionally, under MHCA Chapter III, Section 5, every individual has the right to issue an advance directive. It lets people select how they desire to be cared for and treated for mental diseases.<sup>xviii</sup> The Supreme court, in the year 2018, has also issued specific guidelines regarding advance directives and living will<sup>xix</sup> and the way the individual wishes not to be treated and taken care of in the future. People can still not register their advance directives despite the Supreme Court's recommendations due to a lack of standard processes to execute the SC regulations at the state and national level.<sup>xx</sup> The Vidhi Centre for Policy Research noted in a recent paper that carrying out the directive before a judicial magistrate first class and a three-tiered approval procedure for accurate decision-making is extremely difficult. As a result, very few people can successfully implement the Advance directives.<sup>xxi</sup> In dementia, there is an additional practical obstacle to enacting an advance directive. Unlike many other countries, family members in India may be reticent to discuss the patient's disease prognosis, making care planning difficult.<sup>xxii</sup> Early during dementia, an advance directive and an advance care plan must be completed. In contrast, dementia is usually diagnosed in advanced stages. As a result, the affected person would have developed significant cognitive impairment and could not participate in advanced care planning or make an advance directive.

Furthermore, the MHCA fails to consider the patient's current desires when evaluating advance directives.<sup>xxiii</sup> When patients lose the ability to make decisions for themselves, their present preferences may be ignored, and only an advance directive should be considered. It is possible

for patients undergoing "normalcy/cognitive intact state" or early dementia to not be aware of their future life trajectory when making advance directives. It is also possible for patients' tastes to change over time.<sup>xxiv</sup>

## THE LEGAL LANDSCAPE IS CHANGING

To comprehend how the law reacts to dementia, one must first understand how the law views autonomy. The classic liberal idea that "the person is sovereign over himself, over his own body and intellect"<sup>xxv</sup> is firmly rooted in the common law tradition, which is realised via accepting the individual's right to autonomy or self-determination.<sup>xxvi</sup> Within this traditional formulation of autonomy, capacity is the critical dividing point. According to Buchanan and Brock, capacity is used to "separate individuals into two classes: (1) those whose voluntary decisions must be recognised and acknowledged as binding by others, and (2) those whose voluntary decisions will be set aside and for whom others will function as surrogate decision-makers."<sup>xxvii</sup> After proving that a person lacked capacity, classical liberalism lost interest, resulting in weak conceptual and legal frameworks.<sup>xxviii</sup> The person who lacks capacity become a 'non-person' for whom others make decisions, usually based on an objective (though mainly unmonitored) assessment of their best interests.<sup>xxix</sup> In the long run, this 'autonomy dogma' might substantially limit other rights.<sup>xxx</sup> At least theoretically, the above simplistic distinctions of the common law are no longer acceptable. This shift in legal perspective has two independent sources, and these inconsistencies can cause dispute, especially in dementia.

The first significant source of change was the recognition of precedent autonomy in the 1980s, which recognises that people with capacities can direct, to varying degrees, the fate of their incapacitated selves.<sup>xxxi</sup> The MHCA provides for an advance directive,<sup>xxxii</sup> often known as a lasting (or everlasting) power of attorney, which empowers someone to make decisions on another's behalf in the case of incapacity.<sup>xxxiii</sup> The advance directive, if any, should comply with the regulations issued by the MHA-2017, the Central Mental Health Authority. Even the courts have applied precedent autonomy; for example, in *Common Cause (A Regd. Society) v. Union of India*<sup>xxxiv</sup>, the Court recognised advance directives in healthcare as a method to delay and remove life-sustaining treatments from terminally ill patients. This entails respecting their previous exercise of autonomy, even if they can now do so due to their current position

(conditions such as dementia, for example). However, the effectiveness of both sets of measures in protecting precedent autonomy has been questioned across the globe.<sup>xxxv</sup> The reason is that even if an individual's current wants to contradict their former actions, their decisions made while they had the potential for integrity and sincerity should be honoured.<sup>xxxvi</sup> In the event of dementia, the personality might alter to such an extent that previous autonomy loses much of its ethical value without reversal.<sup>xxxvii</sup> Critics of precedent autonomy claim that it is sometimes possible to argue that the person who wrote the advance directive (or otherwise expressed opinions before developing severe dementia) "is not the same person as" the person about whom we must now make a decision. She is virtually a different person as a result of the alterations. In this instance, the initial autonomy concept will not apply. Instead, the legislation should be written to balance the patient's earlier choices, as documented in an advance decision, communicated to family or proxies, and their current wants, values, and necessities.<sup>xxxviii</sup> In addition, advance directives have been criticised as ineffective while giving people with mental illnesses far too much freedom over their mental health treatment and care.<sup>xxxix</sup> The second driving force for change is the growing significance of human rights treaties in capacity development, such as the European Convention on Human Rights (ECHR)<sup>xl</sup> and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>xli</sup> These instruments demonstrate that a lack of capacity does not entail a loss of rights. The measures are more concerned with the individual's present circumstances than with previous decisions. In respect of the ECHR, the European Court of Human Rights has recognised the relevance of the right to liberty<sup>xlii</sup> and the right to physical and psychological integrity<sup>xliii</sup>, independent of capacity.<sup>xliv</sup> In this regard, the European Court of Human Rights has given growing respect and recognition to an individual's (present) will, notwithstanding their lack of capacity.<sup>xlv</sup> The CRPD protects many important rights for people with dementia, including the right to liberty and security, freedom from exploitation, violence and abuse, respect for physical and mental integrity,<sup>xlvi</sup> and the right to live independently and participate in society. In the case of dementia-related cognitive impairment, Article 12 is of great importance. According to this Article, states must recognise that "persons with disabilities have a right to legal competence in all aspects of life on an equal footing with others." All measures connected to the exercise of legal power, according to international human rights law, must also include suitable and effective safeguards to avoid abuse. Measures relating to the exercise of legal capacity must respect the person's rights, will, and preferences, be free of conflicts of interest and undue

influence, be proportional and tailored to the person's circumstances, be in effect for the shortest time possible, and be reviewed regularly by a competent, independent, and impartial authority or judicial body. Many commentators believe Article 12 represents a "paradigm change" in the law's approach to capability.<sup>xlvi</sup> According to them, Article 12's language "represents a shift from the traditional dualist model of [mental] capacity versus [mental] incapacity," instead of establishing a "philosophical foundation on which to ground the positive duty of the state to maximise autonomy for people with significant intellectual, cognitive, and psychosocial disabilities."<sup>xlvi</sup> Both the RPWDA and the MHCA preambles demonstrate that the CRPD is included in both pieces of legislation. As a result, much of the material in these two Acts is meant to give many of the CRPD's specific components immediate impact. For example, the RPWDA recognises individuals with disabilities' equal legal ability and includes provisions on the property, financial affairs, and the nature of informal assistance agreements. This statute also addresses formalised support arrangements in a limited guardianship.<sup>xlix</sup> In a limited guardianship, formalised support arrangements are also addressed in this law.<sup>l</sup> The MHCA, on the other hand, makes no mention of physical or mental health. Even so, the paradigm shift of the Act from replacement decision-making to supported decision-making through nominated representatives and previous instructions might aid in keeping the Act's integrity intact. The MHCA affirms individuals' right to make healthcare choices 'perceived by others as inappropriate or wrong'<sup>li</sup>, providing they have capacity. Advance directives can take effect when someone loses mental competence.<sup>lii</sup> Several additional sections of the MHCA maintain Article 12 of the CRPD, which requires states parties to "ensure that all measures relating to the exercise of legal capacity provide for suitable and effective safeguards to avoid abuse per international human rights law." When carrying out their duties, a nominated representative must consider the 'current and past wishes, the life history, values, cultural background, and the best interests of the person with mental illness,'<sup>liii</sup> and if they believe coercion was used, a Mental Health Review Board can change or cancel an advance directive.<sup>liv</sup> The MHCA's definition of the least restrictive care choice aligns with the CRPD's proportionality principle.<sup>lv</sup> The MHCA's nominated representative requirements are, on the whole, stricter than the RPWDA's restricted guardianship standards. While the current statutory stance is an improvement above the common law position, it falls short of effectively protecting the rights of those who lack capacity. Finally, while looking at India's mentally ill and disabled situation, it is important to note that various discriminatory laws do not ensure equal treatment

under the law. Many of these statutes have not been altered, and neither the MHCA nor the RPWDA will object. Even so, while broader, multi-level reform of such other legislation is essential, careful, pragmatic use of the MHCA and RPWDA might speed many changes. As a result, capacity roots persist even as the legal landscape shifts. Building a legal framework that protects rights and acknowledges the needs of persons who lack capacity is still a work in progress. With this in mind, it is important to consider the difficulties that might arise when employing a capacity-focused strategy in the setting of dementia.

## **CHALLENGES IN USING A CAPACITY-BASED APPROACH TO DEMENTIA**

Any legal approach that uses capacity as a criterion for rights recognition is problematic. However, the obstacles vary depending on the type of capacity constraint, so it is vital to pay attention to the specifics of each case. Three difficulties in the context of dementia deserve further attention. Three problems in the context of dementia deserve a more in-depth consideration. The first is assessing decision-making competence. The second is finding inconsistencies between an individual's past wishes/values and present preferences. The third is determining vulnerability without a formal determination of incapacity.<sup>lvi</sup> Recognising these problems with a capacity-based approach serves two functions. It serves as a reminder of the limitations of such an approach to dementia and the need for fundamental reforms in the legislation. It also allows for considering more urgent practical ways to ease concerns. Although the law (and conventional liberal thought) has tended to consider capacity determination as a factual inquiry, a capacity judgement represents a balance of two essential competing objectives: improving the patient's well-being and respecting the person as a self-determining individual. There are two dimensions to this decision. The development of a capacity standard is the first, more overtly normative part; the application of this standard in practice is the second. Under the Mental health care Act 2017, capacity is determined functional and decision specific.<sup>lvii</sup> While this method has evident benefits in reducing interference with decision-making autonomy, it is best suited to situations where one-time, substantial judgments are required, such as permission to surgical intervention. The strategy is less closely matched with the assortment of less dramatic, day-to-day decisions that might mean the difference between the maximum and minimum autonomy, as well as the improved



or worsened quality of life for a dementia patient.<sup>lviii</sup> The Mental Health Care Act's capacity requirement, which is mainly per that used at common law, demands that the individual grasp and retain information relevant to the decision to be made; utilise and balance that information in making the decision, and convey the decision.<sup>lix</sup> The decision in Samira Kohli has since been followed in medical negligence cases. It has been understood to imply that the doctor should furnish adequate information regarding the treatment to the patient before their consent can be considered valid.<sup>lx</sup> This high threshold has been criticised as being "cognitivist and rationalistic" and neglecting to consider factors like emotion, identification, and narrative.<sup>lxi</sup> It is, however, tempered by many factors: first, there is a presumption of capacity; second, the incapacity must arise from an impairment or disturbance in the functioning of the mind or brain before this standard is applied; and third, a person may not be considered unable to understand if they can realise an explanation given appropriately in their circumstances. These criteria, together with other safeguards establishing that capacity cannot be decided only based on a person's age, appearance, or health, or simply because they make a poor judgement, are intended to protect persons from being wrongfully declared incompetent. However, their efficiency in this area is debatable due to a lack of efficient enforcement methods. While the statutory requirement provides the legal foundation for capacity judgments, the individuals who provide care on the ground are generally responsible for ensuring that the legal standard is met. In the case of dementia, this may need a formal evaluation by a geriatric expert; at the least, it will entail an assessment by a caregiver, whether a family member, a friend or a professional caregiver.<sup>lxii</sup> The MHCA's underlying assumption that every Act in connection with a person's care or treatment must be preceded by a determination of capacity and best interests is a legal fiction. The reality is far less organised.

Despite efforts to convey information to carers and other relevant parties through the Code of Practice, there is very little data on whether and to what degree the legislative framework has indeed infiltrated practice. Although it is easier to monitor the more formal, professional assessments of capacity, the data in this context is still relatively limited. In India, for example, there are 0.75 psychiatrists for every 100,000 persons. There are around 9000 psychiatrists in India, with 700 psychiatrists graduating each year. This works out to 0.75 psychiatrists for every 100,000 persons. This is less than the required number of psychiatrists per 100,000 people, at least three. Furthermore, while many trained psychiatrists and psychologists are in metropolises and large cities, there is a considerable imbalance in the distribution of

psychiatrists and psychologists.<sup>lxiii</sup> Moreover, the psychiatric community fails to recognise advance directive evidence as a useful instrument for supported decision-making and exercising legal competence, as recognised by the MHCA. Such data suggest that professionals are not particularly effective in carrying out the task, whether because of a lack of legal knowledge or because they apply the legal standard in practice. These difficulties are, of course, not unique to the geriatric context; however, given that the demographic variable most associated with findings of incapacity is age, difficulties in determining capacity are especially worrying in this context.<sup>lxiv</sup> Capacity determinations in dementia are also made more difficult because of structural factors, such as passivity conditions in nursing homes and, sometimes, by the grief and dislocation that accompanies the loss of a long-term life partner. These difficulties with determining capacity in dementia can, to a degree, be countered through better empirical research into the assessment process employed and more informed practitioners.<sup>lxv</sup> Even if there is progress, the fundamental problem remains because customised estimates of competence are not trustworthy predictors of individual rights. Keeping Past and Present Interests in Check As previously noted, the change toward a more inclusive attitude to persons with capacity impairments is based on two pillars: higher acceptance of antecedent autonomy and greater respect for human rights. The law is pushed in distinct ways by both conceptual bases; the former emphasises the previous (competent) self, whilst the latter is primarily concerned with the present self. While this is unproblematic in many situations involving decreased capacity, there may be difficulties in the setting of dementia. Even if there is no direct contradiction between prior beliefs and current interests, it is evident that the role of a person's former life and how they will be remembered is much more likely to be ethically significant in the context of dementia than in most other circumstances of diminished capacity.<sup>lxvi</sup> The MHCA provides little assistance in balancing one's past and present selves, just requiring that both sets of perspectives be considered. However, the work presents particular obstacles in the dementia environment, which must be addressed on their terms. When a person satisfied the criteria for capacity, their decisions were generally beyond the reach of the law. Therefore, the law has tended to avoid engaging with broader questions of decision-making agency, preferring instead to shoehorn questions of agency into the test for capacity. Nevertheless, many of the issues in dementia can more accurately be defined as matters of agency rather than capacity.<sup>lxvii</sup> A person with dementia forced to choose between continuing to live at home with an abusive adult child or life in a nursing home can hardly be

described as an autonomous agent, notwithstanding whether they meet a legal standard for capacity. To date, the main way in which the law has engaged with agency questions is through the developing jurisprudence on vulnerability as an aspect of the Court's inherent jurisdiction. Munby J<sup>lxviii</sup> defined a 'vulnerable adult' as someone who may be unable to care for themselves or protect themselves from severe injury or exploitation, whether or not mentally incompetent and suffering from any mental disease or mental disorder. As expressed in these broad words, this would allow for broad use of the Court's inherent jurisdiction to intervene in decision-making. As such, the establishment of vulnerability-based inherent jurisdiction raises real concerns.<sup>lxix</sup> However, expanding the inherent jurisdiction also answers an essential need not fulfilled under the capacity-based approach. Our agency, or decision-making freedom, relies on variable degrees on our social environment, including various structural determinants. This dependency is inadequately represented in the employment of individualist, capacity-based procedures. Focusing on vulnerability as a foundation for overriding people's choices may be squandering the possibilities of a vulnerabilities-based strategy. Vulnerability, according to Fineman, is inherent in the human experience, and while 'our vulnerability occasionally, and perhaps even eventually, ends in weakness, or bodily or emotional degeneration,' vulnerability can also be generative, presenting opportunities for 'innovation and growth, creativity, and fulfilment.'<sup>lxx</sup> He further argues<sup>lxxi</sup> that the quality and quantity of resources available to each topic determines how vulnerable they are. Recognising vulnerability may lead to a debate of the nature of a responsive state and establishes links between the vulnerable subject and the state and its institutions. In this way, focusing on vulnerability allows for a legal strategy that tries to remove underlying limitations to an agency rather than labelling vulnerable people as "other," as the traditional capacity-based approach did. Thus, recognition of vulnerability may be related to wider concepts of capabilities-building and the purpose of creating the skills and the environment within which human autonomy may thrive. In practical terms, this demands legal involvement not only with persons but with surrounding activities, questioning if they increase or undermine autonomous capacities. In this way, the legal lens expands beyond the individualist focus that dominates how the law deals with dementia.

## CONCLUSION

One of the primary arguments addressed in this article is that the law must treat dementia-related matters on their terms rather than as a component of a broader capacity/incapacity agenda. This is not to deny the possibility that improvements in the law on competence may evolve the legal environment for those with dementia. The UN Convention on the Rights of Persons with Disabilities encourages creative approaches to capacity. Its emphasis on aiding allows for a more holistic approach to decision-making. The CRPD has a fair deal in common with the capacities approach, which broadens the lens of involvement and understands that external influences may hinder or improve the human agency. This is morally and legally relevant. The intellectual foundations for the law regarding dementia have progressed a significant distance in the previous several decades; it is now time for the law to catch up. The evolving jurisprudence surrounding 'vulnerability' offers one means of addressing this, but a great deal more work has to be done to build an acceptable legal framework in this area.

## ENDNOTES

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- <sup>l</sup> Section 14.
- <sup>li</sup> Section 4(3)
- <sup>lii</sup> Section 5(3)
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- <sup>liv</sup> Section 11(2)(a)
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- <sup>lvi</sup> Foster, Herring and Doron (n 6).
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