



## Debating Point

### Capable People: Empowering The Patient In The Assessment of Capacity

#### Introduction

Medical writing on assessment of a patient's mental capacity, or competency, to make decisions about treatment tends to uncritically adopt an approach in which the doctor controls the timing and method of assessment. Such an approach has three main implications. First, it precludes or inhibits the patient's power regarding his or her mental status. Secondly, it affects his or her decision-making capacity in respect of health care generally. Thirdly, it reinforces the unequal, but alterable, power relationship between doctor and patient.

The traditional approach to assessment of capacity reveals a limitation to the principle of self-determination, which is advanced by many commentators as the ethical purpose against which assessments of mental capacity are determined. Patients' interests in having their power and control over decision-making recognised, honoured and facilitated are not adequately protected by the principle of self-determination, or its close relation autonomy and the remaining principles in the hegemony of modern liberal bioethics; beneficence, non-maleficence, and justice (the 'Georgetown Mantra'). A theory and practice of patient empowerment is necessary to protect and promote substantial interests patients have over this aspect of decision-making. Empowerment may serve further, and different, interests in health care encounters. Empowerment recognises that prior to any ultimate decision regarding treatment for which a competent consent, or refusal,

is required, a patient can, in appropriate circumstances, have his or her ability to develop that capacity better fostered and protected by

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respecting his or her power and control over essential aspects in the lead-up to and process of assessment.

#### Traditional Purposes of Assessment

At one level, the assessment of capacity serves to distinguish the mentally capable from the mentally incapable patient. The capable patient can thus exercise her freedom to choose whether or not to go through with treatment, and, if so, which of a range of options to prefer. Much of the writing on determination of mental capacity treats the standard of capacity as unproblematic and, thus, renders invisible the normative context and sociological implications of capacity assessment. In this literature, capacity is treated as constituting a self-evident either/or determination or one where debate centres on narrow issues such as whether the patient is able to understand or actually understands. A determination of capacity establishes an important contour point on the landscape of medical encounters. Since determinations of capacity to make decisions about health care and treatment are not made universally in all episodes with health care consequences but only when a person enters or is captured by the medical

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system, the determination of capacity marks the person out from her social hinterland and signals a particular status in medical terms. This may have important individual, social, legal and medical consequences.

While much discourse on assessment of mental capacity assumes a value-neutral base, a number of authors acknowledge that the assessment of capacity, specifically the standard of capacity, involves a normative issue. American psychiatrists Appelbaum and Roth state that the standard ought to be determined by the policy-oriented goals one is seeking to attain:

'...[s]uch goals inevitably include a mixture of concerns relating to the societal values that we wish to implement and to the preferences we wish to confer in these values'.<sup>1</sup>

Appelbaum and Roth describe several goals: autonomy, rational decision-making, beneficence, respect for persons, justice, encouragement of research, subject satisfaction, and test administration. Gillon, English disciple of the Georgetown Mantra in Britain, states '...it appears reasonable to argue that at least in democratic, and hence in principle autonomy respecting, societies there seems no good reason for doctors to establish any higher (or lower) standards of requisite autonomy than those set democratically'.<sup>2</sup>

A more detailed exegesis of the value purposes underpinning the standard of capacity is undertaken by Buchanan and Brock.<sup>3</sup> They advance two principal values as foundational to the standard of capacity: individual well-being and self-determination. Self-determination is posited for two reasons. First, it is instrumentally valuable in promoting a person's well-being. Secondly, it recognises that most people commonly want to make significant decisions about their lives for themselves because they believe that in most cases they are in a better position to decide what is best for themselves than others are. Beauchamp and Childress argue, however, that capacity is determined primarily by whether a person has the capacity to decide autonomously, and not by whether a person's best interests are protected.<sup>4</sup>

The medical ethics literature reveals a range of approaches to the doctor's role in the assessment of capacity. Beauchamp and Childress adopt a

traditional biomedical model, in which incapacity is viewed in terms of physical cause, restoration of which lies with the doctor through biophysical intervention:

'... if a health professional has determined that a patient is not competent, the next step is to inquire whether capacity can be restored. When incompetence rests on a reversible cause, such as pain or overmedication, the immediate goal is to restore capacity prior to decision-making'.<sup>4</sup>

Such an approach locates power in the health professional by marking his or her authority over the determination, thus privileging his or her (biomedical) means of assistance, and defining resolution in terms of medical professional knowledge rather than, or in addition to, patient-centred knowledge.

Buchanan and Brock are among the few authors who espouse a doctor's duty to promote capacity. They write:

'... [t]he attending physician is responsible for making every reasonable effort to maximize the patient's competence (by appropriate control of medications, by improving the patient's ability to communicate through the use of special techniques or equipment where appropriate, and by making a sincere effort to provide relevant information to the patient in a manner which he or she can understand and evaluate and in a decision-making context which is supportive)'.<sup>3</sup>

Here, the emphasis is on the doctor controlling the process. Though the advice is couched in terms of the doctor improving the patient's ability and providing information in a supportive context, the locus of power and direction resides in the doctor.

Seedhouse offers a practical approach to autonomy in patient decision-making.<sup>5,6</sup> He emphasises the doctor's role in improving or enhancing (what he terms 'creating') autonomy. He defines autonomy as being 'able to do'. This is distinguished from 'respecting autonomy', which entails agreeing to fully reasoned choices of others. This occurs at a point which Seedhouse calls the 'autonomy flip'. Until this point, he states, 'the health worker (it needn't be a doctor) does not judge that the subject has

sufficient autonomy to respect. Once the flip has occurred then the doctor is, normally, obliged to desist ...<sup>7</sup> The health worker's responsibility is, as soon as possible, to ensure that through the enablement process the person or group can take over.<sup>7</sup>

Seedhouse alludes to the relation between autonomy and power when he states that:

'... [a] significant element in any true health care intervention will be to lessen impediment and to create power in the person who is being cared for'.<sup>5</sup>

He develops this further elsewhere by noting that while 'a person with some degree of autonomy is able to control at least part of his world, the person without autonomy is powerless'.<sup>8</sup> He proposes that where there is a conflict between the need of the individual seeking 'more health' and the health worker genuinely attempting to create further autonomy, 'the way to resolve this is to assume that the individual has a clearer view of what will empower her than the health worker unless there are very good reasons to doubt this'.<sup>8</sup>

A further rare exception to the general trend is the recent British Medical Association/Law Society guidance on assessment of mental capacity.<sup>9</sup> The guidance states that it is the general duty of the assessing doctor to maximise capacity. It lists useful points relevant to this duty. These include treating any condition which affects capacity before a final assessment is made; minimising the impact of any mental disability (for example training a person with short-term memory deficit); choosing the best location and time for the assessment; and, educating the person being assessed as to the factors relevant to the proposed decision. While this guidance has a patient-oriented, facilitative approach to assessment, it remains bounded by a paternalist/beneficence model of the doctor-patient relationship. For instance, while it recommends that doctors choose the best location and time for the assessment, the patient's place in determining these matters is omitted. Medically established knowledge precludes patient control over this aspect of decision-making. The guidance states:

'... [i]n someone who is on the borderline of having capacity, anxiety may tip that person into incapacity. It may be appropriate to assess the person in his or her own home if it is thought that an interview at either a hospital or a GP's surgery would adversely affect the result'.<sup>9</sup>

These truisms exclude an equally important, and necessary, source of knowledge—the patient. That the patient's knowledge is rendered invisible by the guidance is further illustrated by its final comment that:

'... [a] relative or carer may be able to indicate the most suitable location and time for the assessment'.<sup>9</sup>

Thus, with regard to this important aspect of assessment, the patient's exclusion is complete. He or she becomes voiceless.

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The BMA/Law Society guidance does, however, recommend at length the importance of the doctor educating the person being assessed as to the factors relevant to the proposed decision. Here, the doctor is enjoined to establish what the patient understands about the decision and re-explain, in writing if necessary, aspects of the decision which have not been fully grasped. This advice is consistent with the law on consent to medical treatment, though it appears to go further by recommending that the doctor check patient understanding and provide written clarification, if necessary. The BMA/Law Society advice locates decision-making power and control in the doctor. There is, for example, no acknowledgement that the patient may question the assessment process or initiate complementary or different modes of approaching the assessment.

To summarise, the literature on assessment of mental capacity reinforces the power and control of the doctor over the patient, although Seedhouse disavows physical control and maintains that a health worker's enablement of autonomy cedes at the 'autonomy flip'—when the person or

group can then take over. This general reinforcement of power and control in the literature is so whether the issue of assessment is treated as value-neutral or normative. Those authors who analyse capacity in normative terms locate the determination against traditional principles; self-determination, autonomy, and well-being. The literature on capacity shows that even when there is resort to such principles, patients are effectively denied a voice over key elements in a capacity assessment, including location and timing. The formal goals of self-determination—promotion of patient autonomy and choice—can be seen to break down in the literature and guidance on capacity assessments.

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A fresh approach is required. The concept of empowerment is attractive. It represents an effective means by which to complement the benefit to patients afforded through the principle of self-determination and associated facets of the various meanings of autonomy. It would also catalyse the latent power of a linguistically open term such as self-determination, much in the same way as rights discourse in the USA has advanced actual patient rights in decision-making.<sup>10</sup> More importantly, a theory and practice of empowerment acknowledges the unequal power relationship in the doctor-patient relationship and locates greater control and power in the patient. While there will remain circumstances in which the patient is deemed incompetent to make decisions about medical treatment, in these cases the doctor or appropriate proxy decision-maker will continue to make decisions in the patient's best interests. The application of the concept of empowerment respects the patient's ability to develop his or her ultimate functioning, aided where necessary by medical, social and personal resources.

### **Patient Empowerment**

Generally, the term and practice of empowerment exists across a range of fields, principally mental health advocacy,<sup>11</sup> and within distinct

organisations, particularly nursing<sup>12</sup> and social work.<sup>13</sup> However, its usages within these fields and organisations reveals a term whose purposes and applications are invariably problematic and sometimes contradictory.<sup>14</sup> Servian, for instance, proposes that empowerment occurs where individuals are able to follow their own interests, to feel fulfilment or to meet their own material needs.<sup>15</sup> This appears to be insufficient. Such a definition might equally connote liberty or freedom—quite different concepts to empowerment. Moreover, controversy surrounds the issue of who would empower. Some nursing literature, for example, uncritically assumes that nurses can empower the patient.<sup>16</sup> This claim is advanced despite substantial sociological literature on the different roles of nurse and patient, and in particular, the professional and institutional constraints experienced by nurses in their relationship with their patients. Such a claim by nurses also assumes that empowerment is appropriately effected by health care providers. Many patients, consumers or clients within the health care sector challenge the idea of professional control over the process of empowerment.

### **Empowerment: Theoretical Starting Points**

The term 'empowerment' is adopted in this paper as a response to the unequal power relations in society generally, with particular reference in the present context to the disequilibrium of power between medicine (understood as medical knowledge and professional practice)

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*'... "empowerment" is a response to the unequal power relations in society generally'*

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and health care patients, clients or consumers. It draws from wider sociological attempts to understand professional occupations in terms of their power relations in society<sup>17</sup> and in terms of authority to construct modes of medical knowledge.<sup>18</sup> This theoretical approach would be open to seeing individuals as having some ability to apply power rather than to see individuals in health care encounters, as Lukes<sup>19</sup> and Foucault<sup>20</sup> might suggest, as necessarily victims of other people's power.<sup>15</sup>

## Empowerment and Capacity

My focus on capacity is an attempt to isolate one of the events in doctor–patient relations where power issues are at stake. In this context empowerment starts from acknowledging power relations, honouring a patient's actual and/or potential power in decision-making, and respects a patient's exercise of greater control over the process of assessment. Control here does not mean domination. Rather, it conveys effective involvement and authority in communication and decision-making. Control is not necessarily equivalent to an autonomous decision to consent to or refuse medical treatment. It is embedded in a process rather than an isolated event. It may serve as a vehicle by which an autonomous decision on a proposed treatment or series of treatments is achieved. It can be viewed, to paraphrase from the psychological literature on self-control:

'as a process through which an individual becomes the principal agent in guiding, directing, and regulating those features of his [sic] own behavior that might eventually lead to desired positive consequences.'<sup>21</sup>

Roberts *et al* treat powerlessness in the health care encounter as an absence of control. In their study of the effects on a small sample of patients of negotiated and non-negotiated nurse–patient interactions, they found that subjects in the negotiated group expressed greater perceptions of control over decisions occurring within the interaction than did subjects engaged in a non-negotiated approach. The feeling of control was a function of the interactive approach with the caregiver, and not based on subject personality alone. While the study did not show that the perception of empowerment affected agreement with treatment, the authors suggest that studies may show that nurses could, by increasing patient's responsibility for and involvement in their treatment, be instrumental in improving patient compliance and satisfaction.<sup>22</sup> Empowerment would seek to address the complexity of psychological factors implicated in decision-making which arise from, and could be remedied through, the dynamics of power. For instance, learned helplessness theory casts light on the inhibition of human action through

historical explanation of lack of control and negative consequences following attempts to gain control.<sup>23</sup> As Servian points out, this may be relevant to empowerment when:

'... [c]arers and users in many cases may feel stigmatised by historically unresponsive and uncontrollable services'.<sup>15</sup>

This may affect patients' requests for support and their decision-making ability generally. An empowerment approach would seek to respond to the patient's sense of powerlessness by addressing these psychological (as well as structural) inhibitors. Conventional doctrine on self-determination and patient autonomy tends not to do so, though in fairness it should be added that modern conceptions of self-determination and respect for autonomy in medical ethics generally did not attempt to do more than secure limited, though laudable, objectives for patient decision-making.<sup>24</sup>

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This awareness of the complexity of decision-making reflects recent developments in action theory. While different meanings are attached to action theory, a common denominator reveals an aim to analyse human action broadly, in response to the historically narrow approaches of philosophers, jurists and psychologists, particularly behaviourists.<sup>25,26,27</sup> It incorporates examination of volition, intention, goals, means, potential consciousness and responsibility;<sup>28</sup> informed, though not necessarily jointly, by sociological, psychological<sup>29</sup> and philosophical<sup>30</sup> perspectives. In addition to its sensibility to complexity, it is relevant to the present discussion because some of its proponents explicitly acknowledge the importance of addressing the issue of power in decision-making both at an individual level<sup>31</sup> and in terms of social action.<sup>32</sup>

Empowerment also goes beyond the atomistic individualism of self-determination and patient autonomy by recognising the need for individuals to have access to resources, including affective support, needed to effect their own

control.<sup>33</sup> Internally, the patient experiencing disrupted capacity may need to adjust and find a new, or re-establish a familiar, centre from which to make clear, autonomous choices. Externally, the patient may need to control influences on capacity. For instance, Alderson observes in the context of children—a group traditionally assumed to be incompetent—that some facing surgery used patient-controlled analgesia pumps or practised their own hypnosis, which 'literally put the child in charge'.<sup>34</sup> Old people, disillusioned with conventional medicine and health care, have achieved improvements in self-care decision-making through empowering initiatives such as peer health counselling, advocacy and support groups for Alzheimer's sufferers.<sup>35</sup>

Crucially, however, the aim of empowerment is mediated by the need to respect each patient's well-being and long-term autonomy. At least from the perspective of allegiance to professional codes and avoidance of liability, the doctor who intends to respect a patient's power in the lead up to and process of ultimate assessment of capacity regarding treatment would need to be satisfied that the patient is mentally capable of doing so. Empowerment, therefore, acts on and fosters autonomy while also respecting patients' greater control over the process of assessment.

### Empowerment: Beyond Self-determination and Autonomy

A range of meanings have been given to the term autonomy. Gerald Dworkin summarises this diversity well:

'... "autonomy" is used in an exceedingly broad fashion. It is used sometimes as an equivalent of liberty... sometimes as an equivalent to self-rule or sovereignty, sometimes as identical with freedom of the will. It is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests... It is related to actions, to

beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles. About the only features held constant from one author to another are that autonomy is a feature of persons and that it is a desirable quality to have.'<sup>36</sup>

Hill takes a more systematic approach.<sup>24</sup> He distinguishes between distinct, though related forms of autonomy, including the germinal sense in which Kant used it in his *Groundwork on the Metaphysics of Morals* as a property of the will of rational beings to act in accord with principles. Hill also refers to Sartrean autonomy, to the sense of autonomy as the ideal rational life, and to the modern concepts of autonomy as a psychological capacity and as a right. A hybrid of Kantian and the latter two concepts inform the more recent bioethical constructions of autonomy by Veatch,<sup>37</sup> Beauchamp and Childress,<sup>38</sup> and Gillon.<sup>2</sup> The osmosis of bioethical discourse into law has further altered the meaning of autonomy and brought it closer to, if not sometimes synonymous with, doctrine on self-determination.<sup>39</sup> As such it is reduced to a right, principally to refuse treatment, if the criteria for autonomous decision-making are satisfied. Generally, these are understanding, belief and choice.<sup>40</sup> Seedhouse rejects what he sees as a narrow conventional view of autonomy.<sup>5</sup> He advances a position on autonomy as an intrinsic quality of people. Seedhouse espouses 'creating autonomy' and acknowledges the place of power in enabling autonomy. The literature generally on autonomy, however, does not address power, in particular the dynamics of power as this affects the patient's decision-making process, and autonomous choices.

Empowerment also goes beyond the narrow focus on rationality in the discourse on self-determination and patient autonomy by recognising the person's power in respect of cognitive and effective functioning. Such empowerment serves to facilitate each person's individual fulfilment, with wider implications than that suggested by rational choice. As Feste notes, 'the empowerment model speaks of self awareness, personal responsibility, informed choices, and quality of life'.<sup>41</sup> The reference to 'personal responsibility' does not, however, abandon the patient to looking after herself alone. An

important dimension to empowerment is that it fosters knowledge of, and reliance on, self in relation to the interdependence of all resources, human and other. Patient autonomy and self-determination on the other hand historically favour individualism and privilege.

The development of self-awareness and the process of taking control is consistent with the notion of self-help, and is indeed often conflated with empowerment. Empowerment loses its political edge, however, if it is seen only as another form of self-help or enablement.<sup>42</sup> While the ends of empowerment may share some relations with self-help, a radical and vital aspect of empowerment lies in its recognition of the power relations between doctors and patients. Even recognition alone is less effective than empowered action.<sup>43</sup>

### Group and Social Empowerment

Much of the literature on empowerment emphasises empowerment at a number of social levels of interaction and action. Athena McLean, while noting the operation of empowerment at an individual level, also identifies three further levels: (a) group—involving self-help and mutual aid; (b) organisational—effecting change in the social community; and, (c) consumer—securing greater funding and promoting advocacy.<sup>44</sup> Action at all these levels may help to effect patient empowerment in respect of capacity assessments. Consumer action, through, for example, representative groups such as the National Association for Mental Health (MIND), can help in altering the power relations between medical professionals and patients by influencing legislation (as was the case with the Mental Health Act 1983 in England and Wales) and by promoting the confidence of, and resources for, patients and users of mental health services.

Group meetings may be a particularly useful method for empowerment in institutional settings, such as residential homes, where lack of extra-institutional stimulation, traditional ageist attitudes, and a relative absence of independent support from consumer organisations impedes the actualisation of individual and collective power. Ward and Mullender advance self-directed group-work as a powerful

facilitation of empowerment.<sup>45</sup> They note that with the focus on the individual the weight is too strongly distributed in favour of individual uniqueness and private troubles. They state that a number of distinctive benefits follow from self-directed group-work. Personal troubles can be translated into common concerns. Group

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solidarity engenders strength and dissolves previous apathy. A range of voices offer, and foster, alternative explanations, options for change and improvement. Self-directed group-work can also lend itself to an anti-oppressive style of working from which participants have an experiential base to challenge oppressive practice. Rappaport, writing about mental health, suggests that individually oriented interventions may actually impede their allegedly empowering mission in so far as their limited expectations reduce the self-esteem of individuals and increase their feelings of worthlessness and despair.<sup>46</sup> He calls for a wider view of empowerment that is sensitive to the various contexts in which a person is found over time.

Group empowerment may be particularly important among social or cultural groups who experience their power with an emphasis on the collective rather than on the individual. Professional or institutional practices which effectively remove such peoples from their social network can disempower them, with resulting harmful effects on functioning and, in particular, on decision-making capacity. In the context of children's capacity, Alderson challenges the traditional Piagetian approach to cognitive development whose unconscious influence permeates much discussion about competency. She states:

*'... [c]ompetence is more than a skill, it is a way of relating and can be understood more clearly when each child's inner qualities are seen within a network of relationships and cultural influences'.<sup>34</sup>*

Alderson states that some of the one hundred and twenty 8–15-year-old hospital patients in

her survey on capacity wanted to be the main decider, some wanted to share in decision-making, while others wanted their parents and doctors to make decisions for them.

Patient empowerment may be informed by methods of long-term enhancement of capacity. McLaughlin refers to the Jean Vanier-inspired L'Arche residences in which people with learning difficulties share their lives with others, with (mutual) advances in capacity.<sup>47</sup> McLaughlin notes that it often takes years for people with learning difficulties to overcome the accumulated toll of institutionalisation and over protection but that when it happens, they begin to engage once more in trial and error learning and make substantial gains in functioning ability and competence.

Patient empowerment will, no doubt, be enhanced if accepted by health care providers and supported independently of the health care system. Independent support is increasingly provided by advocacy workers committed to principles of empowerment in mental health. Health care providers are also increasing the scope of independent patient advocacy in hospitals. The legal protection of patient's interests and rights in medical decision-making may also serve to empower the patient. Recent ground-breaking legislation regarding consent to medical treatment in Ontario, Canada, is particularly relevant to the current discussion of capacity. The legislation establishes a framework within which advocates are proposed to defend and advocate the interests of persons in community and institutional contexts. It also provides, including reference to determinations of capacity, certain rights of notification, entitlement to a rights advisor, and review.<sup>48</sup> Elsewhere, advocacy is advanced as a valuable resource in empowering patients and users of health services.<sup>49</sup>

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*'... espousal of a catch-all concept of empowerment which fails to account for disparities in class, race, gender and education will privilege some patients over others'*

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However, espousal of an apparently catch-all concept of empowerment which fails to account for disparities according to class, race, gender and education will privilege some patients over

others, thus reinforcing social inequities. Moreover, that assessment of capacity may be biased or impaired by culturally determined ideas of illness or intelligence and by communication difficulties between participants with different ethnic or cultural backgrounds<sup>50</sup> suggests the need for context-sensitive empowering strategies. For instance, group encounters among similarly affected individuals can raise consciousness about, and action in response to, such specific power issues in medicine.

## Conclusion

Traditional medical writing on patients' capacity to make decisions reinforces the unequal power relation between doctors and patients. This is most clearly shown by medical control over the general process of assessment, particularly timing and location. When commentators discuss capacity within a context of normative principles, the main principles, namely self-determination, patient autonomy and well-being, do not address power at all, or, if they do, do so insufficiently.

Patients' interests in having greater control over the process of capacity assessment are substantial and pressing. A determination of incapacity can not only carry a social stigma and injury to self-esteem,<sup>51</sup> but may also leave an individual feeling angry and resentful,<sup>52</sup> particularly where he or she feels denied the opportunity to take responsibility and control in the process of assessment.

While amendment to principles of self-determination and patient autonomy and concepts such as self-help and enablement may go some way towards alleviating the problems surrounding self-actualisation, only the theory and practice of empowerment challenges and offers solutions to the power and control of the medical professional over decision-making. This is illustrated in the context of assessment of capacity by advocating that patients exercise greater control and responsibility over the timing, location and use of resources (material, emotional and social). Such power can be facilitated at a number of levels: individual, group, organisational and consumer. Some writers believe that empowerment must be

taken and cannot be granted. Realistically, however, the success of any theory and practice of empowerment in medicine requires acceptance from medical professionals as much as patients, not least because courts tend to rely on medical opinion in adjudications about capacity.

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