

Notes on Capacity and Decision-Making

A Background Paper

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***"The Disability Rights Model and Guardianship:
Mutually Exclusive or Compatible Concepts?"***

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"People do not consist of memory alone. They have feeling, will, sensibility, moral being. It is here you may touch them, and see a profound change."¹

The principal of personal autonomy is an important foundation of the American legal system, as well as of most people's notions of human rights, globally. The right to make decisions about our life directions – what we choose as our life's work and partners, where and how we live, what if any spiritual path we choose to take, and so forth – is something we hold as precious. In the domain of our personal health care, involving our very beings and lives, the right to make decisions about what medical treatment we accept and decline is something we hold particularly dear. Reality, however, places at least two obstacles in the way of our obtaining what we decide we want. The first involves the availability of affordable care, but that is a problem for another arena. The second involves the individual's intellectual, cognitive and emotional ability to make decisions about our medical care. For most of us, for most of our lives, such capacity is assumed. Even when faced with complex decisions about alternative treatments for a life-threatening illness, no one presumes that, ultimately, at the end of all the discussion and research, the decision is not ours alone to make. However, decisions at end-of-life must often be made under circumstances where the individual's capacity to make decisions is impaired or questioned at least to a degree. It would be as inappropriate to act on the basis of the announced decision of an incompetent person, as it would be to refuse to accept the position of one who has full

¹ Neurologist A.R. Luria, from Dr. Oliver Sacks' *The Man Who Mistook His Wife for a Hat and Other Clinical Tales*.

capacity. Under such circumstances, how as a practical matter is the individual's right to consent or withhold consent to medical treatment to be maintained?

The existence of any degree of mental impairment forces us to confront three questions.

- Is the degree of impairment such that the individual is, in the terminology of the new Massachusetts guardianship law, unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance?
- If the individual is unable to make or communicate decisions about his medical care, who is to act on his behalf?
- Upon what should the substitute decision-maker base his or her decision? I will address these questions in turn.

A. Regarding the degree of impairment, the assessment of capacity may start with a clinical assessment but, as a legal matter, the question and its answer involve many considerations. For one thing, competency has emotional as well as cognitive components. While an individual may have the capacity to evaluate the facts of a given situation, we really cannot consider her to be competent if her decision-making is ultimately the product of paranoid delusions. But what of the more commonly encountered situation of the elder individual who indicates that she will go along with whatever a child, or the attorney, says? Where a real or imagined fear of loss of a relationship motivates a decision, rather than any sense of balanced self- and family interest? Similarly, depression in even a moderate degree may affect the ability of the individual to engage fully in decision-making.

There are also environmental or circumstantial considerations in assessing capacity. An individual in familiar surroundings may be able to function adequately in decision-making, whereas the same individual, newly admitted to a hospital or nursing home, may be utterly confused. Late afternoon can be a terrible time for people with Alzheimer's disease. An individual with even severe bipolar disorder may be perfectly competent while on her medication, and perfectly incompetent while off. Understanding may be affected by fatigue or the occurrence of an unpleasant or disconcerting event immediately before the meeting. What of the individual who can hear you if you sit opposite her or spoke on her good side, but won't acknowledge the problem? The individual who can't remember the details of a meeting without a written summary?

A given individual may be able to understand and make decisions in some domains, but no others. For example, an individual may be able to manage day-to-day with most requirements for daily living, but not have the ability to make meaningful

decisions about his or her medical care. An individual may be incapable of making decisions on financial matters, but understand enough of what is involved in signing a health care proxy or signing a Will to render the execution knowing and therefore valid.

Some factors may directly impinge on the individual's capacity for decision-making, but not relate to competency at all, in a legal sense, for example, lack of experience, knowledge or information, or physical constraints on vision, hearing or language. This is perhaps one of the most important aspects of determining the capacity of the individual with mental retardation, with respect to the question of whether he or she has the capacity to sign a health care proxy.

Cultural perspectives on autonomy and on the relationship between the individual and the family may substantially affect decision-making in ways that may not be apparent to attorneys drilled in the rugged individualism of American legalisms, particularly informed consent.

Drawing from the wide legal and non-legal literature on the topic, a number of abilities are suggested as underlying an individual's capacity to make decisions about his health care:

- To understand the individual's role in the decision-making process; that is, that the individual has a choice.
- To possess the requisite basic cognitive skills to receive, store, recall and process information, including one's own past experiences, which are necessary for meaningful decision-making under current circumstances.
- To understand the likely results of a decision, as well as the less-likely but possible results.
- To appreciate the implications of alternative courses of action for one's objective future, as well as one's subjective goals and values.
- To weigh the advantages and disadvantages of alternative courses of action.
- To maintain stable choices long enough for them to be effectively implemented.
- To formulate short-term and long-term objectives in relation to health care.
- To distinguish between immediate and long-term needs, and to plan accordingly.
- To apply past experience to new situations.
- To recognize the general quality of personal relationships, e.g., in distinguishing between relatives, friends, strangers.

- To communicate decisions effectively, whether through non-verbal or verbal means.

We should not base a finding of incapacity based on the presence of functional limitations in one sphere, where residual functioning in others is adequate. Non-verbal communication can be as effective as speech. The presence of even a severe degree of disability does not in itself put the issue of participation to rest. To the contrary, the more severe the disability, the more responsibility devolves to parents and others to take affirmative steps to facilitate participation -- to make, in the terms of the Americans with Disabilities Act, "reasonable accommodations" to the individual's areas of incapacity. This may require, for example, greater understanding of and reliance on the particular communication modes displayed or preferred by the individual, whether or not verbal, to ascertain the individual's preferences.

Sometimes, a client will require only an extra measure of preparation, patience, common sense, a willingness to engage and follow-up, without being patronizing. Beyond that, the nature and extent of possible accommodations are limited only by sensitivity and creativity. A few suggestions, suggested by the author for attorneys dealing with clients of limited capacity, but probably adaptable to any circumstance where participation in decision-making is sought to be maximized:

- Find out what you can about the presentation of the client's impairments in advance of the initial meeting.
- Ask whether any special accommodation should be made for the meeting due to the client's special needs. Send materials in advance of meetings when feasible.
- Think about the physical setting for meetings in which the individual is most likely to feel comfortable and focused -- the neutral/professional ground of the office, or the familiar ground of the home. Clients with mobility problems may require shorter meetings, special transportation arrangements, or sessions other than at the office - at home, or in the hospital or nursing home.
- When scheduling a meeting, try to avoid days in which the client is already scheduled for medical appointments or other activities that may leave him fatigued or stressed in anticipation. Ask about the optimal time of the day for the client to function cognitively and emotionally, since this may make an enormous difference in the client's stamina and ability to participate.
- Think about participants for the meeting. Give the client the option to involve trusted family members or friends in any meeting (although also make it clear at the outset that for ethical reasons you must at some point spend time with the client alone, as well.)
- Work from a written agenda where possible. Number your points.

- Engage the client by sitting directly across from him, rather than at the head of the table. Maintain eye contact. Emphasize to the client as well as family members present that you are representing her alone in the family, and that she alone is the decision-maker. Do not overestimate the impact of expectations.
- Listen to the client's narrative. Be attuned to his voice, values and sense of relationship with family members. Communicate in plain and simple language, in short sentences. Break information into meaningful chunks. Speak slowly. Avoid jargon, acronyms and legalese. Stay focused. Avoid information overload. Avoid bringing up tangential matters or details beyond the need of the client in making the decision at hand. (That is, suppress the temptation to show off knowledge.) Encourage questions. Invite discussion. Ask for feedback, illustrations and restatement of information. Repeat information as needed.
- The client with a cognitive deficit may well have great difficulty understanding and remembering factual and technical information. Do not give up on communication in these situations, however. Psychologists say that the capacity of people with Alzheimer's Disease, for example, to communicate non-verbally, by expression, motion, and emotion, can persist effectively even after verbal communication is seriously impaired. Try to understand more than the words, or lack of words, of the client. And try to communicate in a way that gives the client a sense of assurance that you understand his needs and are committed to helping him - in short, that the matter is under control.
- Whenever feasible, reduce evaluations, findings and recommendations to writing, or to audiotape, to permit the client to review them as often as desired to facilitate recollection and understanding. Letting the client know, at the start of the meeting, that you will do this can relieve pressure on the client to remember details or take notes, and thus make client participation in the meeting more effective.
- If the client also has a visual impairment, send the client written materials in larger print fonts. Give the client ample time to read written materials, or read or summarize them aloud if necessary. Be prepared to provide ample follow-up communication to ensure sufficient understanding. If the client is blind, ask what accommodation would be most appropriate.
- If the client has a hearing impairment, position yourself for best effect to optimize hearing. Keep your lips visible. Enunciate clearly. Speak up as necessary, and speak slowly.
- Maintain a normal on-going relationship with the client, to the extent possible, particularly in maintaining communication.

B. Regarding who decides on behalf of an individual who lacks the capacity to make medical decisions himself, in most cases it is the person previously designated by the individual under a Health Care Proxy.

Under Massachusetts law, and under similar laws in most states, an individual who is 18 years of age or older and who has the capacity to do so, may execute a legal instrument designating a health care agent, as well as one or more alternates, to make health care decisions for him if, for any reason and at any time, he becomes unable to make or communicate those decisions.

Nobody – even your spouse or children -- has a right or priority to be named. The only limitation is that you cannot name the administrator, operator, or employee of a health care facility such as a hospital or nursing home where you are a patient or resident unless that person is also related to you by blood, marriage, or adoption.

The health care agent has the authority to act only if and when your physician determines that you are unable to make decisions on your own, and makes an entry in writing in the medical records to that effect. The cause might be temporary (while under anesthesia during surgery) or indeterminate (if in a coma or late state illness).

Unless you limit the agent's authority, it is very broad – basically to make any health care decision you could make were you able. The authority ordinarily does extend to making decisions about withholding or withdrawing life-sustaining care, in the context of terminal illness, coma, or irreversible brain injury or disease. The agent also has the authority to get any information, including confidential medical information, necessary to make informed decisions for you.

Massachusetts has had a health care proxy law since 1989, and by now the advantages of having one have been sufficiently widely recognized that it is unusual to come across a case where no proxy statement has been signed and is available. In situations where no proxy statement has been signed, where the statement has been lost, or where the designated agent and alternates (if any) are not available, recourse to the court for a guardianship appointment may be the only recourse to ensure full and appropriate decision-making on the individual's behalf.

C. Regarding how the health care agent or guardian is supposed to make decisions on behalf of the incapacitated individual, the rule in Massachusetts as in most states is based on a subjective approach, whereby the agent or guardian is to do his best to step into the shoes of the patient and assess treatment options from the patient's perspective. This approach is referred to as "substituted judgment." It means that, to the extent that the individual's wishes, perspectives, morals, values and religious beliefs can be ascertained or reasonably inferred from past statements, actions and decisions,

these personal considerations should guide decision-making, whether or not the course of action would generally be considered best from a medical point of view.

Consistent with this approach, only secondary attention should be given to a more objective assessment of “best interests”, under which decisions should be based on a determination of what, from the perspective of family and professionals, would be best for the individual, balancing the potential risks, benefits and side effects of alternative courses of action.

Leading court cases illustrate how difficult it is to apply these models in actual life circumstances. For example, in Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417 (1978), the court struggled with the application of the “substituted judgment” approach to the circumstances of an individual with severe mental retardation seemingly lacking the capacity to make or communicate the decision as to whether he should undergo chemotherapy for cancer to prolong his life somewhat, where treatment would necessarily involve stressful side effects and physical restraints the purpose of which he could not comprehend. The court, without possibility of communication from Mr. Saikewicz or evidence based on past behavior, nonetheless decided against treatment on the basis that Mr. Saikewicz would have reached this conclusion had he been able. Objectively, the proposed treatment had its potential benefits, risks and side effects. Subjectively, however, Mr. Saikewicz’s inability to appreciate the need for physical restraint, or to rationalize severe side effects in light of the promise of future medical improvement, were seen as controlling the ultimate decision on treatment.