

## Making the Law Match the Reality; Making the Reality Match the Law

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The purpose of this paper is to discuss the importance of the rule of law in democratic societies. Many of my examples come from Ontario, Canada because that is where my experience lies, but I have spoken to enough people and visited enough places to know that the problems are universal.

In Ontario, decisional capacity for many purposes is defined by legislation and a substitute decision-making regime is set out. Decisions about health care treatment and nursing home admission are both covered by this regime. The law sets out a scheme for determining capacity and clearly states that the starting point is a presumption of capacity. The law also establishes a clear hierarchy for substitute decision-making. In brief, the substitute decision-maker for a person found to be incapable is the highest ranking individual on a list of potential substitutes who is available, willing and capable of making that decision.

The Supreme Court of Canada, the highest court in the land, has stated clearly and unequivocally that the capacity test is to be applied objectively and that a capable person has the right to make a decision for him or herself with which others would disagree. In the case of a substitute decision-maker, there is a legal process that allows the professional to, in effect, appeal the decision of a substitute decision-maker that he or she finds objectionable. The law allows the professional to disqualify a potential substitute on the basis of an objectively reached opinion with regard to a potential substitute's capacity but does not otherwise allow the professional to pick and choose among potential substitutes.

That's the theory, anyway.

According to the reasons for decision in a recent case before the Ontario Consent and Capacity Board, the tribunal charged with adjudication under the legislation, things played out somewhat differently. In those reasons, a health professional was cited as having given evidence to the effect that, quote, "his definition of capacity reflected whether he thought the substitute decision-maker was acting in the best interests of the person who needed to be admitted to a care facility" and "that in his view the legal definition of capacity was irrelevant to the consent process." He guided his approach based upon whether or not consent was given or refused in accordance with what he thought was in the patient's best interests" As he explained, "We try to obtain the best result for the patient."

This is the sort of thinking that I want to talk about today. I will come back to this decision later in my remarks but first permit me to set the stage.

Jurisdictions everywhere have struggled with mental health law since psychiatric institutions were founded. Capacity and substitute decision-making legislation has become an increasingly hot topic as our societies age. One problem with this area of law is that society has never really been clear in its own mind just what it wants to accomplish with this whole area and what it thinks about the people who are subjected to it.

We have never been clear in our own minds if we have psychiatrists, and medications, and programmes, and laws, and institutions to assist our fellow citizens who have tragically fallen prey to illness; or if we are dealing with a group of undeserving people who are somehow damaged or inferior as the result of moral or religious failing, or whether we need to control this group because they threaten our safety and create an unsightly and unpleasant situation in our town squares.

A similar level of complex ambivalence influences our thinking about issues of decisional capacity. Do we want our health care professionals to make decisions for us because they know best and will do the best for us? Do we want to let them determine our fate because that is their right as befits their station in life, or are we committed to informing ourselves and making our own decisions because to do so affirms our independence and autonomy and the right to control our own bodies and fates?

Are we committed to preserving life above all else because of our commitment to a religious or philosophically-rooted belief in the sanctity of life or do we believe the right of the individual to decide when to end suffering and make a dignified exit from a life that has replaced meaning with endless suffering?

And we live in capitalistic societies. Control over one's own property is considered a fundamental right. Transfer of control over property from the owner to a third person is a big deal in our world. We assume that we can only do it to protect the person from him or herself. But historically this was done in order to protect the interests of the sovereign by preserving an incompetent person's assets and estate so that family members would not become charges on the public purse. So here again we see the confusion and ambivalence.

Underneath all of these questions is the more fundamental question of who really owns the health care system and its institutions and for whose benefit it ultimately exists. In plain English, whose turf is it, anyway?

If all this were not enough, we have the cultural issues and assumptions that underlie all of the legislation and practices in question. These cultural challenges exist on several different axes. For example: We have the different world views and languages of the physicians, ethicists, lawyers, policy makers and politicians. Frequently, they don't think like each other, talk like each other or trust each other. The assumptions that underlie their work profoundly differ from one group to the other. And when an area of endeavour, such as this one, involves all of them on the same playing field, things are likely to get messy.

In fact, if I can continue with the playing field metaphor for a moment, we have one team on the field playing basketball, one playing lacrosse and one playing football, all at the same time. No wonder they don't understand each other, interact very well or even respect each other. They can't even agree on the rules, the underlying assumptions, the purpose of the game or even which game they are playing.

But there are other cultural players as well. Both mental health and consent and capacity legislation are laden with cultural assumptions. These assumptions relate to how society is organized, the concept and importance of individual autonomy, the role of family, the way important decisions are made and a host of other issues. Our consent law, for example, presupposes that there are two layers to our society: the individual and the state. Family members are relegated to the role of substitute decision-makers bound by the rules established by the state, and, arguably, nominees of the state. Substitute decision-makers, for example, are bound by statute to take into account the values and beliefs of the patient but forbidden to make reference to their own values and beliefs when making their decision. (As an aside, I am not at all sure how this is even supposed to work unless we introduce robotics into the substitute decision-making scheme.)

Cultural assumptions also underlie our concept of decisional capacity, a construct based on the assumption that you are either fully autonomous or stripped of all control over your affairs in a particular sphere. Nowhere does our model accommodate the ideas of shared decision-making and consensus management that are so fundamental to so many cultures such as Canada's own aboriginal peoples.

For all of the reasons already mentioned, and many more, mental health and capacity law reflect a delicate balance taking competing interests and philosophies into account. Some have referred to the process of creating these laws as an attempt to reconcile the irreconcilable. Mental health law, for example, allows us to apprehend and detain citizens who are not accused of any crime. In Ontario, it does not require court authorization. This is a very unusual authority in a democracy. At the same time, there are extraordinary powers of review and supervision of the committal power. All of this exists because mental health law is about trying to balance the need for safety and treatment, on one hand, with the right of every citizen to liberty, autonomy and self-determination, on the other. What some see as technicalities, others see as necessary protections.

Consent and capacity law allows a health practitioner proposing a treatment to make a legal determination that I am not fit to make my own decisions. This, in turn, allows the professional to seek out a substitute decision-maker who will make decisions for me that are so fundamental as to sometimes determine whether I will live or die. Or whether I will be allowed to return to my own home or have to spend the rest of my days in an institution not of my choosing.

No individual, no matter what his or her education, credentials, or status or standing in the community has the right, without legal authorization, to hold me against my will or interfere with my body in ways or for purposes that I have not consented to. In a democratic society there is only one way to balance all of these competing interests. That is through the rule of law. Outside of judge made law that is designed to deal with certain closely defined emergency situations, there is only one body that can authorize a citizen's detention or treatment against their will. All of these powers, of course, are reserved to the people themselves through their elected representatives in parliament. In the case of Ontario, for example, the parliamentary body in question is our provincial legislature.

We see then, that the family doctor or emergency room physician or psychiatrist who decides to hold me against my will, or sign paperwork to that effect, may only do so under the authority of power granted to him or her by the people through their elected representatives in parliament. Again, with a few minor judicially sanctioned exceptions, there is no other way. And, it stands to reason, that there must be strict limits and appropriate checks and balances in the exercise of such powers. The fundamental principles of democracy demand no less. Just like we oversee the armies and police and jails that deprive people of their liberty and, sometimes their life, against their will and demand strict parameters, oversight and control, so must there be parameters, oversight, and control over those health and helping professionals who, for the most beneficent of reasons, seek to restrict our liberty, control our property, or interfere with our bodies.

I am sure that few would dispute my conclusions to this point in the paper. They are self-evident to anyone weaned on the milk of democracy. But yet no one seems to scream loudly when these fundamental and self-evident principles are not followed. In fact, many of us scream bloody murder when we are not allowed to flaunt these principles in the name of some supposed greater good. At the outset of my remarks I provided one example of a professional who appears to believe that he is not bound by the rule of law in making determinations that will result in the permanent institutionalization of his client. From the remarks, one can safely conclude that he believes that he is morally justified to ignore the rules established by society in order to achieve some greater good for his elderly and vulnerable client. He is not alone. I set out a few more examples below.

Ontario laws have two sets of procedures for making findings of financial incapacity. These findings have the effect of removing control of a property from the person and placing it in the hands of a state official. The usual procedure requires a specially trained fee-for-service professional known as an assessor to attend and examine the person. The assessor is required to explain why he or she is there and the subject is entitled to reject the assessment. This procedure applies to anyone in the province over eighteen years of age.

There is also a much simpler procedure that has the same effect. This procedure is carried out by a physician so there is no need to contact an assessor or wait a few days for the assessor to arrive. There is no direct cost to the individual. And the patient has no right to refuse. The only problem is that this procedure may only be used for a bona fide patient under *the Mental Health Act* in a hospital recognized in law as a psychiatric facility. The law is very clear that only a person who is legally detained in a psychiatric facility against their will or who has given voluntary, informed capable consent to voluntary psychiatric status is considered to be a psychiatric patient. The law could not possibly be any clearer. The fact is, however, that the procedure is routinely used for grannies admitted to orthopaedics after a hip fracture. The fact that this is totally illegal, a terrible violation of personal rights, and, arguably, fraudulent, has apparently not crossed many people's minds. The office of the Public Guardian and Trustee sent out a bulletin a few years ago in an attempt to address the matter. The memo helped a bit but did not stem the tide.

A finding of incapacity to make a nursing home admission decision can have momentous implications for a person. In Ontario, such a finding can be made by any physician, social worker, nurse, psychologist, etc. The effect of such a finding is to remove from the person the right to make their autonomous decision as to where they will spend the rest of their life and transfer the decision-making power to a third party. The authority to make this finding is clearly quasi-judicial although it is never thought of as such. The law sets out a clear definition of capacity that must be followed in conducting the evaluation. The courts, up to our Supreme Court of Canada, have repeatedly made it clear that the process is a very serious one and that objectivity, clear-headedness and proper documentation are the rules of the day. The courts have also made it clear that an appropriate amount of time must be devoted to a capacity evaluation to allow the necessary inquiries to take place and the appropriate persons spoken to.

None of this, however, has stopped the routine use of nurses and social workers employed as hospital discharge planners from performing this function. Many of them are poorly trained in capacity evaluation or not trained at all. A high number of them are told to ask a few pro forma questions and tick off a few boxes on a form instead of conducting a proper capacity evaluation. More troubling is the fact that many of them are in a conflict of interest so serious that they should never be allowed to conduct capacity evaluations in the first place. What I mean by this is that many discharge planners are under enormous pressure to clear hospital beds by moving the elderly out of the door. It is simply inconceivable that anyone subjected to this sort of pressure should be allowed to make a capacity evaluation when the result of that finding may well determine the speed with which the patient will depart the hospital.

A person admitted to a nursing home theoretically has all the rights of any other citizen. But it often doesn't work that way. Their treatment decisions are often made by family members even though no one has even bothered to assess the resident's decisional capacity, let alone make a finding of incapacity. In fact, treatment decisions are frequently made by house physicians who don't bother to get consent from either patients or their families.

In one recent scandalous case, a complaint was made against a

physician who routinely ignored the clear legal obligation to get informed consent before treating nursing home patients. He was, however, successful in defending himself before the profession's self-governing body by arguing that it was standard practice among physicians in nursing homes to ignore the requirement for informed consent to treatment. Now, I understand that if I complain against my doctor for mismanaging my ulcer treatment, she can legitimately and reasonably defend herself by saying that she followed accepted practice. But that is quite different than arguing that a clear violation of legal requirements is excusable on the basis that others are scoffing at the law as well. Then again, maybe we should all adopt that defence. Just imagine. The boys up at the lake who are ticketed for heading out in their boats after drinking five or six beers could just tell the judge, "Your honour, I am innocent 'cause all the guys do it."

And the list goes on.

Our *Mental Health Act* allows the detention of an individual for an assessment of up to seventy-two hours. This assessment must take place in a hospital legally recognized as a psychiatric facility. The individual's rights under the *Canadian Charter of Rights and Freedoms* must be honoured by providing a form that explains his or her status and rights. Anybody outside of a psychiatric facility having custody of such a person must transfer them forthwith to a psychiatric facility. But the fact is that many of the receiving hospitals designated as psychiatric facilities are either full or place such a low priority on mental health that they routinely refuse or are very slow in accepting these individuals from outlying hospitals that are not designated as psychiatric facilities. As a result, our smaller hospitals are faced every day with the dilemma of putting their communities and patients at risk by releasing potentially dangerous individuals into the community or detaining them quite illegally and risking prosecution or suit for false imprisonment.

Once that patient gets to the psychiatric facility, there is no guarantee that fundamental legal rights will be respected. The law is clear that I am either to be kept against my will as an involuntary patient, in which case I get rights advice and the right to an appeal, or I am a voluntary patient and can head out the door at will. Many staff people at psychiatric facilities, however, do not like the idea of having to face a legal review. So they have found a trick that allows them to lock patients up without legal recourse. The attending physician simply notes in the chart "certifiable if tries to leave." This puts the patient into legal limbo. He or she has no legal recourse whatsoever or even access to the rights advisor since they are not technically held against their will. On the other hand everybody knows that they cannot leave. This scandalous situation, this wholesale abuse of human rights, takes place every day across our province.

I should also mention the fraudulent ruse of avoiding the mandatory annual tribunal review of involuntary committal by making the patient voluntary on paper for a brief period and then starting the involuntary status again. Scandalous! I could go on all day but I think that you get the point.

This sad state of affairs is not limited to Ontario. I was recently in Israel, a country with progressive mental health legislation and an engaged bar and bench. And yet I was told of a recent case where the courts ordered the release of a psychiatric patient but

the physicians at the hospital decided that release was not in the patient's best interest so they simply moved her to another unit and ignored the court order.

Hungary is another country that we consider to be progressive. Until recently some patients in Hungary were kept in cages. Specifically, selected patients were kept in a contraption known as a cage bed which is a metal bed frame with bars welded around and on top. Cage beds were made illegal a few years ago. Some hospitals removed them. Others replaced the bars with chicken wire and announced that they no longer had cage beds. Net beds, but not cage beds. And they claim that they are now complying with the law.

So why does all of this matter? In addition to the obvious human rights violations inherent in some of the situations described above, I would argue that this state of affairs is a fundamental affront to democratic principles and that it puts the liberty of all of us at risk. In fact, I would argue that it would be better in many ways not to have any laws at all in these areas than to have laws that are ignored. At least, if we had no laws, we would know that we have not legislated and not fulfilled our responsibility. The way it is right now, we can dupe ourselves into thinking that we have dealt with the issue and solved the problem when, in reality, we have done nothing of the kind.

I think that there is something profoundly frightening in a state of affairs wherein we pass legislation in the glare of publicity but then ignore it or violate it away from the bright lights when dealing with our most vulnerable citizens who rely on the legislation to protect their rights. As I noted at the outset, only parliament has the right to legislate in these areas and that legislation, by definition, reflects the wishes of society and a delicate balance between competing interests and philosophies. It is simply intolerable that anyone would take upon themselves the right to ignore these statutory provisions. And the fact that the rest of society ignores these violations is unfathomable and frightening. And I should make one more point. If the laws are being ignored or violated with impunity and on such a regular basis, should we not be asking ourselves if the law needs changing?

I recently reread a paper that I wrote on this topic about fifteen years ago. In that paper I said much the same thing but in a much more measured and philosophical way. I am no longer philosophical about the issue. I am angry and I am frightened. Not just for the rights of those vulnerable people in our hospitals and nursing homes but for all of us and for the fabric of democracy itself.

We need to write our laws in plain English and to ensure that ongoing educational programmes are offered for health and helping professionals. They are not going to absorb the law by osmosis. Law and ethics must be an integral part of the training of health professionals and an important part of their ongoing training. And we have too many laws. And they are too long. Nobody but a lawyer or policy wonk could understand this stuff. If we are to expect health professionals to know it, we have to produce it in manageable quantities.

Unfortunately, there also has to be some meaningful enforcement of standards so that it is clear to everyone that the law is ignored at your peril. And ethicists need to understand that legal compliance is not optional. Too many times I have heard ethicists discuss the law as simply another available option. Most of all, we need to take every opportunity to ensure that we make knowledge of and compliance with the law an integral part of professional practice.

It is always wrong for those who exercise state-granted power and authority over others to do so in violation of the law. It is particularly odious when the law is violated and ignored routinely by those who do so while caring for the most vulnerable members of our society. If these individuals believe that the law is wrong then they are morally obliged to struggle to change it. They are not entitled, however, to simply ignore the law when it suits them.

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