

Building a path that doesn't lead to guardianship

For more than thirty years, various sectors of our Inclusion community in Canada (CACL and its Community Living Association and Inclusion confederates) have been arguing before Governments and the public at large that the notion and practice of guardianship (substitute decision making) not only damages but, in effect, destroys both the public image and the legal reality of people with disabilities as inherently equal members of our society.

CACL and its confederates believe that most current laws in Canada relating to substitute decision making have a discriminatory effect on those people with disabilities who by reason of the severity of their life long disability are almost certainly destined at some point in their lives to be placed under some form of guardianship.

It does not sit well on Canadian society that the severity of one's disability alone can be a legitimate cause for removing one's rights from the age of majority onwards, in effect, for the whole of one's adult lifetime!

Although some Canadian Provinces have adopted relatively progressive decision making legislation, in much of the country, we remain stuck with legislation based on and still reflecting British law of more than 800 years ago.¹ Under that law, the King had the prerogative of protecting property by assuming ownership of property of people whose capacity to manage it was diminished. If the lack of capacity was caused by mental health issues that fluctuated, the property was returned to the owner if and when the owner regained capacity. If the lack of capacity was caused by a cognitive disability for which there were no cures – that would include what we now recognise as intellectual and developmental disabilities – the King retained ownership of the property! Therein lies the origin of guardianship (substitute decision making) as we know it today!

The process of applying traditional guardianship law today appears to be less Draconian than in those earlier days. Yet, the effect of guardianship on those subjected to it has undergone little or no change. Once placed under guardianship one is literally reduced to a legal nonentity. That is because the sole intent of guardianship is to "replace the person" by vesting all authority for decision making in another person, the guardian. Once under guardianship, one can only escape from its practical day to day restrictions and its life-defining stigma of virtual nothingness by proving one's legal capacity. For

¹De Praerogativa Regis. The Statute of the King's Prerogative, Drawn up between 1255 and 1290 according to Walker, N. 1968 (p.25]

people who have difficulty or are unable to speak, read, write or understand what a decision is, why a decision must be made or what its reasonably foreseeable consequences might be, that escape route is not available.

In effect, a finding of incapacity can quickly become a lifetime sentence to legal and social oblivion for people with severe intellectual disabilities. Modern changes to terminology, from incompetency to incapacity, for example, do nothing to change that fact or to enhance the image of a person so labeled.

The notion of "replacing" a person with a severe cognitive disability so decisions can be made, in the opinion of CACL (and Inclusion International), is inconsistent with the intent of both the Charter² and the UN Convention on the Rights of Persons with Disabilities.

As caring Canadians, we must learn what accommodation means in this context and then do it! For example, the Ontario Human Rights Commission has expressed in strong terms the obligation to explore accommodation options with respect to persons with psycho-social disabilities to the point of undue hardship:

"Before determining that a person lacks capacity, an organization, assessment body, evaluator, etc., has a duty to explore accommodation options to the point of undue hardship. This is part of the procedural duty to accommodate under the Code. Accommodation may mean modifying or waiving rules, requirements, standards or practices, as appropriate, to allow someone with a psychosocial disability to access the service equitably, unless this causes undue hardship."³

Surely, the same obligations must apply to people with severe intellectual or developmental disabilities! And surely, they must apply not only in Ontario but in all provinces and territories!

CACL is committed to investing whatever time and resources it can muster in addressing this matter. Families and friends across the country continue to support their family members who could not meet current arbitrary tests of legal capacity (understanding the reasons for the necessary decision and the reasonably foreseeable consequences of making or not making the decision) in the effort to avoid guardianship. Thus, the status of their sons and daughters as equal citizens, is preserved. But there are limits to how far current law can be stretched and many people, despite their supportive families or circles of support are teetering on the edge of the proverbial cliff.

² The Charter

³ (<http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-mental-health-disabilities-and-addictions/16-consent-and-capacity>)

In the 30 year struggle against the destructive effects of guardianship, Supported Decision Making is the name that has been given to the most sought after alternative. Quite simply, supported decision making describes the natural way that most human beings make decisions. Typically, in making decisions, we call upon whatever assistance we feel we need from family, friends or others who might be helpful. Most of us are never required to admit to that support because our legal capacity is never challenged! Yet people with noticeable disabilities are consistently challenged! Regularly, they are called upon to prove they made their decisions alone and unaided. For such people and contrary to the norm for everyone else, that natural human need for support is seen only as evidence of legal incapacity. There is something fundamentally discriminatory underlying this reality!

Supported Decision Making encompasses whatever processes are required to enable the decision to be made without a declaration of incapacity and appointment of a guardian. This natural solution to a universal problem is catching on and unfolding around the world particularly for people who only need better information and more supportive environments to assist them in making their own decisions. Were we, truly, to be the caring society we believe ourselves to be, there would no need to call for guardianship.

In short, universal recognition of Supported Decision Making as the decision making norm is the clear intent of CACL and its fellow members of Inclusion International. The United Nations listened to Inclusion International and agreed. Article 12 of the UN Convention on the Rights of Persons with Disabilities – *Equal recognition before the law* – reflects that understanding. Alone, the first three paragraphs of Article 12 surely provide proof of that intent:

"1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."

That, in a progressive society such as Canada, should be sufficient!

It is evident these days, when we appear before Federal or Provincial Parliamentary Assemblies or Standing Committees or when we meet with our local Members, that great respect is shown to people with intellectual disabilities. Whether or not they are actually present for our conversations or presentations, that respect is noticeable!

There is an awareness of disability at government levels that was not always evident in the past. The Charter and the Convention and the work of organizations such as CACL, CCD and People First, have had their influences on governmental thinking and rightly so.

It is not so evident, however, that the same influence, respect or even consideration guides the writing of new legislation. The people who write legislation are not the people who have met and interacted with people with disabilities and their families and supporters. In fact, the opposite appears to be the fact,

There appears to be a complete disconnect between the politicians and public servants with whom we communicate regularly on a policy level and the public service lawyers who write law! Except where the purpose of the law relates specifically to disability, there is no evidence that a disability lens is used in the writing of new laws. To ensure full compliance with both the Charter and the Convention, that lens should be present and used in all law reform along with the lenses for all the classes of citizens supposedly protected by the discrimination prohibitions.

The fight for true equality will certainly continue. In the meantime, families and friends struggle to support their family members and friends who could not meet the current arbitrary tests of legal capacity.

In so doing, families and their supporters find that it is not necessarily the big life-changing decisions that cause the most effort and frustration for, typically, there are relatively few of those in our lives. Rather, much of the frustration arises from the scores of silly day to day situations that erect barriers that halt or hinder the natural progress of growth and experience for many people with severe intellectual disabilities.

For example, how does one set up or change a telephone number for a person who has moved into his or her own home but does not speak or write? How does one change the address for such a person? How does one cash or otherwise direct a CRA or other Federal cheque in the name of such a person? How does one open a bank account for such a person – a joint account needs both signatures! Never mind the failure on the part of the Federal Government, to date, to deal effectively with this issue with respect to the RDSP. The list is endless! No consideration for people with severe disabilities was in mind when the various *Acts* were in the process of development. The *Privacy Act* and the "*Personal Information Protection and Electronic Documents Act* and the subsequent corporate policies developed by banks and other corporate entities are a complete blurr when viewed through a disability lens!

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How much protection these barriers truly provide is may be questionable. A recent attempt to cancel a component of a telephone service on behalf of two people who neither speak nor write (disclosure: one of them is my son), proved illuminative! They share a house. It has a telephone. It was a hard fought battle nine years ago to get their names into the telephone book without their personal authority but we succeeded, eventually! We were not so fortunate with having the monthly accounts directed to my son and his house mate at the address from which their telephone operates! Their account had to come to me at my address!

Recently, the phone packed up. The replacement we purchased had a built in voice mail system. Thus we needed to cancel the no longer needed monthly voice mail charge on the service bill. It seemed a good opportunity to also try to get the billing address tied to the phone address. I called from my home phone. It was a long conversation but - no luck! I answered numerous questions about my identity and my relationship with my son and his house mate. The fact that I had personally paid the bill every month for nine years was irrelevant! They had no information about that! I asked to speak to a manager! The agent asked me to wait. He returned a few minutes later suggesting that I make these requests from my son`s phone number! I did so the following day. I was not asked a single question about my identity. The changes were made! The bill now goes to my son`s address and the voice mail cost has been removed! There is surely a message here!

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Personal Information Protection and Electronic Documents Act

1. PIPEDA sets out the ground rules for how private-sector organizations collect, use or disclose personal information in the course of commercial activities across Canada. It also applies to personal information of employees of federally-regulated works, undertakings, or businesses (organizations that are federally-regulated, such as banks, airlines, and telecommunications companies).

It should be noted that PIPEDA does not apply to organizations that are not engaged in commercial activity. As such, it does not generally apply to not-for-profit and charity groups,