

"First, do no harm"

Audrey D. Cole (2012)

Many of us in the Community Living movement were influenced by the book *Doing Good: The Limits of Benevolence*, published in 1978. Of everlasting effect on my thinking was a principle articulated by Ira Glasser in his chapter, *Prisoners of Benevolence: Power versus Liberty in the Welfare State*. His cautionary principle demands that any programme designed to assist people who are dependent on others, and on the state in particular, be evaluated "not on the basis of the good it might do, but rather on the basis of the harm it might do" and that only those programmes "that seem to be the least likely to make things worse" be adopted. Such wisdom!

Under such a principle in North America in the mid 1800s we might never have built institutions that have served people so poorly and which are taking so long to eliminate. Once regarded as benevolent, they were believed to be places where people with intellectual disabilities could be trained for life in the community. Under Glasser's Principle we would have realized that only by being included in community life does one learn about it.

Had we been looking for potential harm in 1324, guardianship, as we know it, might never have happened. De Prerogativa Regis, the original English guardianship law still shapes our Substitute Decision Making legislation across Canada today. Using Glasser's Principle we might have recognized that one can't simply replace the person, as guardianship does, if the person is unable to understand or appreciate the question and its implications. Rather, one must protect that person's inherent legal capacity by finding ways to ensure those decisions that are "least likely to make things worse" are made. Had Glasser lived back then, Supported Decision Making, rather than guardianship, might well be today's standard for decision making. It is, after all, the natural decision making process used daily by those of us whose legal capacity is never challenged. Unlike guardianship, it doesn't take away our legal identity as fully participating citizens. Our knowledge of the lives of people with intellectual disabilities has shown us, clearly, that, despite all good intentions, the loss of legal capacity through guardianship is a harm.

It would appear that the Federal Government did not have Glasser's Principle on the table when the Registered Disability Savings Plan (RDSP) was designed. As often happens, the RDSP designers got caught up only in the notion of "the good it might do." And there is no doubt about the good the progressive and generous RDSP might do. Sadly, it won't do the same good for all people with disabilities because nobody noticed the potential harm

in its design. It is not really an "RDSP"; rather it is an "RSDSP," a "registered selective disability savings plan." Participation as a Holder is not open to all people with disabilities; many will only qualify as "beneficiaries." Holder eligibility lies in the requirement for legal capacity. Glasser supporters noticed this error immediately but efforts to address the discrimination have so far been unsuccessful. The door to the status of Plan Holder remains firmly closed to people with severe intellectual disabilities who, personally, would not pass the standard legal capacity test of understanding and appreciating the substance of the Plan and its implications for participation in one's own financial future.

Initially, the only solution for people who could neither qualify as a Holder without question nor initiate a Power of Attorney to designate a Holder, was the appointment of a guardian (Substitute Decision Maker) to hold the Plan for the person with the disability. Attempts by CACL and others to persuade the Government and various financial institutions to recognize this discriminatory element have had consequences.

The upcoming provisions within the Federal Government's Omnibus Bill will enable any "spouse, common law partner or parent" to open and be the Holder of an RDSP for a person with a disability who would not pass the legal capacity test. That looks like an example of "the good it might do" but, once again, nobody was looking for the potential harm. The amendment simply delays the inevitable.

My son's situation is an example: in July this year he will be 48, with only a year to take advantage of the Federal contributions to an RDSP. He could not qualify as Holder but, under the amendments, I would qualify. Already in my mid eighties I am not likely to live forever. In most jurisdictions across Canada, the only way the Plan could continue on my death would be for my son to be declared incapable and for someone to be appointed his Substitute Decision Maker and Holder of his Plan. I will not contribute to the replacement of my son in the decisions that affect his life. The RDSP must be equally available to all our sons and daughters.

We must dust off our copies of "Doing Good...". To complement Glasser's Principle we have a new, powerful tool. Article 12 of the UN Convention guarantees both protection of the presumption of capacity and decision making support. We must alert Governments to their obligations and help them to recognize the avenues they can make available to ensure decision making equality for all people with disabilities.

Audrey D. Cole