

# Representation Agreements and Supported Decision-Making

## Part One - Susan Friday

### BACKGROUND – HISTORICAL OVERVIEW

Prior to representation agreements, the only legal tool available for personal planning in BC was the Enduring Power of Attorney. It did not cover health or personal care matters – it only covered financial, legal and real estate property.

In 1989, a number of community organizations and interested individuals came together and began the Project to Review Adult Guardianship. A joint working committee was established in 1991 combining community members and government representatives to work on this issue<sup>[1]</sup>. In August 1992 the C.A.C.L Task Force put forth a coherent statement on supported decision-making. In addition, a number of BC lawyers were actively involved with community efforts to reform adult guardianship laws. In 1993, the Representation Agreement Act passed third reading in the legislature and it was expected that the Act would be proclaimed into force. However, it was delayed by a number of concerns raised by lawyers and others. Consequently, the delay lasted for seven years and then finally the Representation Agreement Act became effective in 2000.

During the interim period, the Representation Agreement Task Group of the Community Coalition of the implementation of adult guardianship legislation spent a year doing participatory research with citizens whose personal lives could be affected by adult guardianship. A provincial conference was held on Representation Agreements in November 1994 and a legislative sub-committee was formed to recommend policies, regulations or amendments that would address the following issues:

- Protection of privacy
- Making Representation Agreements affordable
- Making Representation Agreements accessible even to the least mobile and most remote citizens of BC
- Making Representation Agreements easy to understand and simple to do.<sup>[2]</sup>

In review, is it evident that the provincial government has historically failed to facilitate personal empowerment of ordinary citizens – especially seniors and mental health consumer/survivors? The Community Coalition's struggle with legislation proclamation comes to mind, particularly with the timing of the Representation Agreement Act vis-à-vis the Health Care Consent Act, Guardianship Act and Office of the Public Guardian and Trustee Act.

The Coalition has long advocated (1992 – 1997) that the Representation Agreement Act be put into effect **before** all of the other acts because of its crucial importance as a first alternative to public guardianship. With regard to necessary amendments, the BC government was reluctant to make any changes prior to the September 1996 proclamation. The Coalition's Representation Agreement Task Group, in its acclaimed Legislative Sub-committee Report, had argued for several modest amendments prior to proclamation.

The main objective of the Community Coalition was to ensure that the new laws would maximize personal, private decision-making throughout an adult's life. The following key social reforms were to be realized:

- ❑ Legal recognition of supported decision-making
- ❑ Status for informal advocacy provided to adults by family and friends
- ❑ Support for capacity rather than assessment of incapacity and,
- ❑ Ensuring new rights of review and appeal in health care consent and care facility admission procedures. [\[3\]](#)

To ensure that the new laws would bring about these important social changes, the Community Coalition focused on several key parts of the legislation: The Representation Agreement Act, the advocacy and appeal provisions of the Health Care (Consent) and Care Facilities (Admission) Act, the responses to abuse, neglect and self-neglect in the Adult Guardianship Act, and the process for assessment of capability that runs through all of the legislation.

And then finally, the Representation Agreement Act came into force in 2000. There were still some amendments that had to be made so that the legislation would work more smoothly and in the following year these became effective. It was a long journey since 1993 – and it still wasn't over. In the Spring of 2004, the community had to defend the Representation Agreement Act against the Ministry of Attorney General. Fortunately, the government listened carefully and agreed not to pursue any reforms.

## The Representation Agreement Act

The Representation Agreement Act is regarded as an effective foundation for all of the new adult guardianship acts. It reflects significant progress in the presumption of capacity – in that an adult’s way of communicating is not, in and of itself, grounds for deciding his or her inability to understand or make decisions about personal care, and health care, financial and legal matters.

The law has changed to include non-cognitive as well as cognitive abilities in the determination of capacity. This is appropriate in view of our human potential to possess more than one type of intelligence.

In reflecting upon the community-based system of care, it is clear that personal capacity is demonstrated in many ways and is further enhanced by supportive relationships. This view has been, and continues to be crucial to the intent of the new legislation – as is expressed in Sections 7 and 8 of the Representation Agreement Act.

The benefits of making and registering a Representation Agreement are as follows:

- ❑ Your wishes are at the center of decisions that affect you
- ❑ You can choose people you know and trust to help you, and
- ❑ They will have the legal power to help you
- ❑ You can save lots of money
- ❑ The government will not get involved in your personal and private affairs.[\[4\]](#)

For mental health consumer/ survivors, it would appear that their wishes are also respected, but unfortunately, they currently remain in a more perilous position. While it is true that there is greater protection against being a “ward of the government,” i.e. living under a “Certification of Incapability,” consumer/ survivors must still go to greater lengths to protect their own best interests. This is because the provincial Mental Health Act has the power to override sections 7(1) c and 9(1) c of the Representation Agreement Act.

A form of Representation Agreement, known as a Ulysses Agreement, offers better protection against hospital detention and forced treatment, especially if a support team is present to deal with hospital staff. This is certainly a step forward, but falls short of a state we refer to as genuine ‘peace of mind.’ While the support team or Representative has some negotiating power with a medical team or psychiatrist - such power may not completely prevent forced treatment, i.e., medication is to be discontinued if it does not benefit the patient...

The following account, of a young man named Mark, is inspiring in terms of recent advances in legislation:

## Mark's Story

Mark had episodes of mood disorder. Each episode created great disruption in his life. Not only did Mark have to struggle to get treatment, but he also suffered unpredictable consequences afterwards. Sometimes his bank account was overdrawn, or he had lost his job or housing. Out of desperation, Mark decided to try a Ulysses Agreement. He asked four members of his extended family to act as his Representatives. He divided their responsibilities into three major areas: health care, financial affairs and employment. He very clearly described the circumstances that would signal his Representatives to act on his behalf and also said what he wanted them to do. His doctor agreed to help.

Mark and his family members executed the agreement. His Representatives have acted on the agreement several times. They've used it to freeze bank accounts and credit cards, to help

Mark get treatment and to manage his personal affairs. The banks and professionals who have been called on by the Representatives have honoured the agreement. In retrospect, Mark says that having a Ulysses Agreement "saved his life." He no longer has to pick up the pieces and start over after each episode of illness.[\[5\]](#)

## Philosophy of Self-Determination

We are accustomed to the idea that self-determination can only be exercised independently. In the context of supported decision-making, that is to say, in the context of relations with others, we see that interdependence is a valid and meaningful way to make choices and decisions. In fact, as individuals, we often confer with others, especially when making important decisions and we find that decision-making is enhanced. It is our natural right to make decisions affecting our lives with the support, affection and assistance of family and friends of our own choosing. According to Schwartz, It is not enough to challenge guardianship as a model of decision-making. "We must also challenge the view of society and humankind that assumes some people are of lesser value and are incapable of making choices about their own lives. Laws and policies which exclude people and provide for "substitute decision-makers" are based on the assumption that individuals are independent as well as separate from one another. Individual rights to self-determination and autonomy are seen as significant from the point of view of being able to exercise those rights independently and without interference. People are categorized and gain status on the basis of their ability to make decisions *on their own*. Those who may be different in some way are categorized differently. Our social and legal systems develop methods of distinguishing people on the basis of their ability to perform to standards." [\[6\]](#)

This categorization is rooted in the false dichotomy of political left versus right, which began during the French Revolution. Our "post-modern" social nature remains distorted within this framework and we need a better context, one befitting our true evolution as a species. If we remain stuck within the current framework, it is to our own detriment since what we have is still a form of social engineering. It is the centuries old view of "us" and "them" which has lingered on into our 21<sup>st</sup> century.

In a society such as ours, which has become increasingly dependent on information transfer, we clearly see that false political dichotomies can be hazardous to one's health. One of the most effective ways to control others is to control the meaning of what is valid information. It is precisely in this way that stigma, discrimination, prejudice and formation of stereotypes become reinforced. If you repeatedly hear that you (and "your kind") are of lesser value, chances are that you will believe it, sooner or later. This becomes self-stigmatization. It is better to be accepted as an equal in the construction of a kinder, gentler society. order to enhance self-determination for people living with

mental health issues, it is important to see the entire person. By doing so, we provide an atmosphere of psychological safety where the person feels free to move in any direction. If you are considered as a person with many possibilities, rather than limits, you are given more space to grow, and thus you will grow faster. By expanding the sphere of valid information to include the most positive messages, free from false dichotomies, we set the stage where we move beyond the former paradigm of guardianship and substitute decision-making into the area of supported decision-making.

## **The Kirby Report**

It is essential to revisit the “Kirby Report” - otherwise known as the Interim Report of the standing Senate Committee on Social Affairs, Science and Technology. How far can we go with the idea of right to self-determination? While there is no question that the necessary practical steps “to ensure justice and beneficence for individuals with mental illness and addiction have not been taken by society,” there is no mention of supported decision-making in this report. In other words, we are brought back to the structure of existing laws that “draw rather rigid conclusions about the presence or absence of decision-making capacity, and the relative inflexibility of changing or adapting protective supervision regimes...”<sup>[7]</sup> What we require are laws and policies that reflect a new set of assumptions about the way decisions are made and how we support people to make choices affecting their own lives. We need to move beyond the old system, where people are classified on the basis of physical or intellectual characteristics (“us” and “them”). The Committee agrees that “there should be more fulsome debate about how to give meaningful effect to a person’s partial and/or fluctuating capacity to make decisions for himself or herself.” This statement sounds positive, although some would say that it remains guarded. The Committee basically concludes with a statement on balance: “An appropriate balance must be struck between the respect owed to the right to individual autonomy and the need to protect vulnerable persons when their decision-making capacity is impaired by reason of mental illness or addiction.”<sup>[8]</sup>

## **The Montreal Declaration**

It is clear that the Montreal Declaration on Intellectual Disability goes further to meet the needs of consumer/survivors. We find the following:

### Section 5a

All persons with intellectual disabilities are full citizens, equal before and under the law, entitled to exercise their rights on the basis of respect for differences and their individual choices.<sup>[9]</sup>

### Section 6b

Under no circumstances should an individual with an intellectual disability be considered completely incompetent to make decisions because of his or her disability. It is only under the most extraordinary of circumstances that the legal right of persons with intellectual disabilities to make their own decisions can be lawfully interrupted. Any such interruption can only be for a limited period of time, subject to periodic review and with respect to those specific decisions for which the individual has been found by an independent authority to lack legal capacity.<sup>[10]</sup>

## **The Road Ahead**

We do not have a comprehensive blueprint for the future and it is not easy to “think outside the box.” However, we see the days are numbered for existing legal frameworks. One reason for this is due to the rapid changes in science and technology. Another reason is the advances being made in ethics, sociology, psychology and economics. While it is true that these “softer” sciences advance more slowly than the “hard” sciences, it is reasonable to assume that our new century will bring about some remarkable changes we can now only dream of.

Evidently, the sphere of mental health will continue to develop in conjunction with the other ones. As mental events become increasingly described in terms of brain structures and mechanisms, society may be obliged to re-examine accepted notions of free will, responsibility and accountability – the so called neuroscience of ethics. Society’s response to these issues will have far-reaching consequences, perhaps as much or more than those related to emerging genetic technologies. However, it is safe to assume that the idea of free will will always be with us.

We are less certain about the idea of “money.” It may disappear over the next few decades, depending on how rapidly our society translates research and development into open social structures. Historically, the use of money has often divided us. Perhaps we are better off without it. Currently, there are 458 billionaires who possess more wealth than half of humanity. Approximately two billion people live on less than two dollars a day. This reality has obvious implications for mental health issues, in terms of inadequate nutrition, psychological and physical safety, social relations, education, employment and housing.

To consider the future of government, it’s not a question of whether some kind of world government should exist - it’s rather what kind it will be. We already have the WTO and the IMF as well as the UN. All these institutions are dominated by rich nations and corporations, but the UN has the best chance of becoming accountable to poor nations and ordinary citizens. The well-being of humanity depends on a new understanding and practice of democracy in a globalized world.

## Part Two - Ron Carten

### Recommendations

As can be understood from the foregoing discussion of the Representation Agreement Act and supported decision-making, the Act offers to people who are not in a position to make informed decisions about their health care (among other things) the right to appoint someone to ensure that their views and wishes are respected. Unfortunately, in the view of the Vancouver/Richmond Mental Health Network, the Act perpetuates discrimination against people with a psycho-social disability.

Section 11 of the Representation Agreement Act explicitly denies to people who have been detained under the Mental Health Act of BC the right to have a representative ensure that their wishes are respected with regard to their mental health care - a right that every other citizen concerned with any other aspect of their health is guaranteed by the Representation Agreement Act. The Vancouver/Richmond Mental Health Network, advocating according to its constitutional mandate for the rights of consumers and survivors of psychiatry, cannot emphasize too much the indignity, the sense of violation, and all the negative characteristics that discrimination carries with it that people with psycho-social disabilities experience under section 11 of the Representation Agreement Act.

This position paper specifically addresses the Vancouver/Richmond Mental Health Network's views of the Representation Agreement Act, which has been fully discussed in previous sections of this paper. This being so, we cannot directly and fully address the discrimination inherent in the Mental Health Act of BC and the Consent to Care Act of BC. Nevertheless, some reference must be made to those Acts if we are to fully explain why we characterize the legislation discussed here as discriminatory and as a violation of human rights.

There are two fundamental reasons why legislation discriminates against people with psycho-social disabilities. The first reason can be referred to as the myth of the violent psychiatric patient. In 2005 it is widely agreed upon in the mental health service provider field and in the community of people who have experienced mental health crises that people who suffer a mental illness are only very marginally more violent than people in the general population. In fact, people who drink alcoholic beverages are far more likely to be violent than people who suffer a mental illness. And yet, this province feels it is imperative that psychiatrists be given the power to not only detain people against their will, but to medically treat them against their will, often under the guise of preventing violence to self or others. There are other groups of people who may be more prone to violence than people suffering a mental illness, but we are singled out for special treatment. This is unfairly discriminatory. However, the argument must be pursued further before it begins to dawn on people how unjust the Mental Health Act, and by implication, section 11 of the Representation Agreement Act really is.

The second fundamental reason why legislation discriminates against people with psycho-social disabilities is the belief that someone who is mentally ill cannot make informed decisions. Of course, this is precisely one very good reason for the existence of a Representation Agreement Act. During the course of the Network's existence many members have shared their stories with others in the Network and one of the recurrent themes of their stories is the lack of respect they receive within the psychiatric system and the poor level of communication they have with psychiatrists and nurses. Without good communication the exercise of choice in health care is an empty concept.

Section 2. subsections a. b and c of the Health Care (Consent) and Care Facility (Admission) Act specifically

deny the universal right of informed consent to people with psycho-social disabilities detained under the mental health act. The reason for this denial of a basic and precious right is at bottom the belief that people suffering a mental illness cannot make informed decisions. Again, the Representation Agreement Act could address this apparent problem, but this solution has been ruled out due to the systemic discrimination found in legislation and in the social institutions that legislation governs.

But how true is it that people with psycho-social disabilities cannot make informed choices? When someone has been apprehended under the mental health legislation, taken against their will from their homes or from the street, when they have been detained (imprisoned) and have had their human right to make decisions taken away from them, it is not unusual for a person in that situation to be angry, unwilling to communicate, and, more significantly, unwilling to trust. On the service provider's side, we must question how respectful and willing to communicate they will be when they need not concern themselves with the wishes or the rights of the people they are presumed to be treating. The imbalance of power that exists in the service-provider/client relationship is fraught with the potential for abuse, mistrust, fear, negligence, complacency and even contempt. We must ask ourselves how such a relationship can be therapeutic. Is rational decision-making going to be fostered in such an adversarial relationship? It is no wonder that people detained under the mental health act are considered intractable, problematic and incapable of making decisions. And it would not be a surprise to find that this "therapeutic" relationship takes its toll on the psychiatrists and nurses who are obliged by law to partake of it.

In short, the Representation Agreement Act, which denies basic rights in this province to people with psycho-social disabilities is not only inherently wrong, it is part of a systemic barrier to the kind of therapy that would work toward healing people who are in a mental health crisis. There are other reasons why discrimination against people with psycho-social disabilities is enshrined in the law of the province, and it would be a mistake to focus on one reason to the exclusion of the others because it is the complex combination of all the reasons underlying discrimination against people with psycho-social disabilities that sustains the current unjust system of mental health care.

Another reason behind discrimination in the mental health care system is the fact that some people with psychosocial disabilities become, in the times of their crises, a very visible public nuisance. One critic of psychiatry has made the claim that this is the primary motive behind the power that has been given to psychiatrists. They can clean up our city streets. In this view, the balance struck between the right to liberty and security of the person, on the one hand, and the right to orderly communities, on the other, has been weighted in favour of the latter. This choice our society's legislators have made has impacted a segment of the population that, up until recently, has had little voice.

Yet another reason behind the discriminatory detention and forced treatment of people with psycho-social disabilities is the wish to help. While those who wish to help others who may be suffering are engaging in a time-honoured and laudable activity, help becomes something quite different when such help is imposed upon others by force. This is precisely the situation in psychiatry. Others (psychiatrists) decide what is good for someone else (patients), and without consulting them impose solutions upon them. These solutions may include unconsented to lengthy detentions, the administration of psychotropic medications, physical restraints and electro-convulsive therapy.

Taken together, the above four reasons that serve as a rationale for current legislation discriminating against

people with psycho-social disabilities, indicate what the population, what the health community and what legislators have believed about the mentally ill. The Vancouver/Richmond Mental Health Network feels it is time that the assumptions underlying how we treat mental illness and some of the attitudes with which we view the mentally ill need to be debated in a public way. We encourage BC MLA's, health service providers, members of the legal community, of the media and of the general public to speak out on the issues addressed in this paper. In particular, we urge the government of BC to amend the Representation Agreement Act so that it does not exclude citizens treated under the Mental Health Act from the right of representation contained within it.

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[1] Hume, Guardianship, in the Networker Vol. 2 Issue 1, 1995 p.5

[2] Community Coalition for the Implementation of Adult Guardian Legislation: Where Do We Stand? April 1996 p.1

[3] Community Coalition Position Paper, p.2 February 1997

[4] .J. Taylor, Transition December 2004/January 2005, p.4

[5] J. Taylor, Ulysses Agreements, Representation Agreement Resource Centre, 2000

[6] D. Schwartz, Report on the C.A.C.L. Task Force on Alternatives to Guardianship, August 1992, pgs. 6-7.

[7] Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Interim Report of The Standing Senate Committee On Social Affairs, Science And Technology – Report One, Chapter 11, November 2004 p.232

[8] Ibid, p. 246

[9] The Montreal Declaration on Intellectual Disability, October 2004, p.3

[10] 11. Ibid, pgs. 3-4