

## The Delicate Dance in Canadian Mental Health Policy: Balancing Equality Rights, Family Rights and Community Rights

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In 1987, two criminologists from Simon Fraser University claimed that, unlike the United States where there had been landmark federal mental health law cases, there had been no Canadian cases establishing constitutional rights to treatment, to refuse treatment, or to receive treatment in the least restrictive environment (Gordon and Verdun-Jones, 1987: 190). Since that time, there have been several important cases that have involved the issues of consent and capacity. There have been several precedent-setting cases in Ontario including *Fleming v. Reid* and *R v. Swain*. Briefly stated, both decisions weakened the authority of physicians and psychiatrists as well as several Charter rights, including freedom of thought according to some critics (Gray et al 2000).

Despite the fact that section 15 of the Canadian Charter of Rights and Freedoms formally recognized and entrenched equality rights for individuals with physical and mental disabilities, the justice system has struggled with cases that have attempted to 'frame' mental health practices as equality issues. This article will focus on a case that went all the way to the Supreme Court of Canada that ultimately was argued on the basis of personal autonomy to make decisions centred on the issue of treatment.

Patients in psychiatric facilities had virtually no say in their treatment until the past twenty years or so. The 'voice' for change in how the mentally ill were treated emerged largely due to several factors including the rise of the civil rights movement(s) in the 1960s and 1970s, the eventual entrenchment of the Charter of Rights and Freedoms within the Canadian constitution, and the rise of the consumer movement. In part, the consumer movement was initially driven by the recognition that radical treatments such as insulin-induced comas, lobotomies and shock treatments were used haphazardly with little regard for the patient in the post-World War II era. Oftentimes, the justification was that the treatment calmed the patient which ultimately made life easier for the medical staff (Simmons 1990).

More recently, there has been a heated debate about involuntary outpatient commitment (IOC). Opponents of IOC argue that the use of this tool was born out of stereotypes associated with mental illness. Despite statistics to the contrary, many fear that mentally ill people are dangerous. There is also a strong belief that forcing the mentally ill to take medication will somehow cure them. However, many of these drugs have powerful side effects. In December 2006,

the New York Times ran a series in which they claimed that drug maker Eli Lilly had engaged in a ten-year effort to play down the health risks associated with Zyprexa, the leading selling medication for schizophrenia. A lawyer representing mentally ill patients had obtained documents and email messages exchanged among top company managers that contained information from doctors related to Zyprexa's links to obesity and its tendency to raise blood sugar – both known risk factors for diabetes (Berenson 2006). The American Diabetes Association, among other critics, claimed that Zyprexa, which was introduced in 1996, was more likely to cause diabetes than other widely used schizophrenia drugs. In 2005, Lilly agreed to pay \$750 million to settle suits by 8,000 people who claimed they developed diabetes or other medical problems after being prescribed the drug (Berenson 2006).

### The Consumer Movement, The Charter and Equality Rights:

As the mental health system in Canada currently works, capable psychiatric patients – those who are considered able to appreciate the foreseeable consequences of accepting or refusing treatment – have the right to make that treatment decision for themselves, whether they are voluntary or involuntary patients (Sklar 2007). As stated by Sheila Wildeman: "The right to make treatment decisions is a basic tenet of health law in Canada and internationally" (Wildeman 2006, 232). Because consumers typically have few material resources and are largely disempowered, advocates of the mentally ill claim that issues of freedom and liberty are extremely important to this population. In particular, because the mentally ill are oftentimes involuntarily admitted to psychiatric facilities, these rights become even more cherished. In Canada, it was not until the early 1970s when patients' rights groups began to mobilize. Mental health consumers organized On Our Own in the late 1970s and established the magazine quarterly Phoenix Rising (Simmons 1990). Other groups included Concerned Friends of Ontario Citizens, the Advocacy Resource Centre for the Handicapped (ARCH) and the Disabled Women's Network (DAWN). One of the policy responses to this negative press was the establishment of the Patient Advocate Program in 1982 in Ontario. The program became operational in May 1983 with the appointment of 11 patient advocates. The mandate of the program was to advance the legal and civil rights of psychiatric patients who were residents of the province's psychiatric hospitals. Other provinces

also established comparable watchdog organizations.

Like members of other illness groups, the psychiatric consumer/survivor rights movement mobilized when former patients began to realize that they had been denied basic legal rights and had been discriminated against because they were mentally ill. Many shared feelings of disenfranchisement and powerlessness in being institutionalized through involuntary commitment and forced treatment. In this important sense, early consumer/ex-patient groups “rejected the medical model of mental illness, professional control and forced treatment and [sought] alternatives exclusively in user controlled centers” (McLean 1995, 1054). Other consumers were more accepting of the medical model of mental illness and traditional treatment practices including medication adherence. Although these individuals came from diverse backgrounds and had somewhat different perspectives regarding the mental health profession, their common experience became the rallying mantra of this new social movement (Frese and Davis 1997). The issue of the right to privacy of persons living with mental illness and the impact of that right on their family caregivers has been contested. After hearing from consumers and caregivers, the Kirby Commission’s Final Report – Out of the Shadows at Last clearly spelled out the dilemma.

With respect to privacy and confidentiality issues, the Committee is well aware that any erosion of privacy and confidentiality protections can have serious negative consequences on an individual’s trust in his or her caregivers. However, . . . witnesses have told us that rigid adherence to privacy and confidentiality rules in certain circumstances can work against the interests of individuals whose mental health is compromised. The unique challenges they describe must be recognized when developing, interpreting and applying privacy and confidentiality rules, so as to allow health care providers and family caregivers to provide patients with the much needed support they sometimes require (Standing Senate Committee on Social Affairs, Science and Technology. Report 1. 2004, 246).

As is the case with all Canadians, people with a mental disorder have the right to be notified of their legal rights under the Charter including notification of why they are being detained, the right to counsel and have the validity of the detention determined by way of habeas corpus. Involuntary patients also have rights under provincial mental health acts including the right to apply to a tribunal such as a Review Board or a Review Panel (Gray et al 2000).

Section 15 (1) of the Charter of Rights and Freedoms states that: Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or physical or mental disability. By specifically including mental disability as a recognized ground of discrimination, the Charter established the federal government as the champion of the rights of persons with a psychiatric disability and dictated that the federal and provincial governments were obligated to protect and promote equality rights (Torjman 2001). Provinces were given three years to bring their statutes into line with the Charter. In Ontario, Bill 190 was finally passed in June 1987 after considerable debate. The original version

of the Bill gave boards of review an override power which was supported by psychiatrists and the medical community. Viewing this as a draconian measure, psychologists, social workers, advocates and patient self-help groups were opposed (Simmons 1990). According to Bill 190, competent involuntary patients had the right to refuse treatment. However, a board of review was given the authority to override the decision of a substitute decision-maker to refuse treatment for involuntary incompetent people.

Even if individuals are involuntarily admitted to a psychiatric ward, they still have their Charter rights. Provincial mental health acts also grant involuntary patients additional rights and safeguards. These rights and safeguards include:

- committal criteria and procedures;
- treatment authorization criteria and procedures;
- rights information;
- renewal certificates;
- review boards;
- the courts; and
- other safeguards (e.g., confidentiality). (Gray et al 2000)

As it relates to involuntary hospitalization, all Canadian jurisdictions permit involuntary admissions for persons who present a danger to themselves or to others. Generally speaking, provinces have tended to adopt either dangerous or treatment models of civil commitment. Some provinces contend that the danger must be of physical or bodily harm. Defenders and supporters of the dangerous model argue that restrictions on a person’s physical liberty and autonomy is only justifiable on the basis of the harm principle. In their view, any other justification is nothing short of discriminatory. Critics of the treatment model – that doctors know best as it relates to treatment – view this model as a paternalistic approach in dealing with mentally ill individuals (McLachlin 2005). However, some provinces go beyond the confines of the dangerous model.

In [other provinces] a broader notion of danger is used and the risk of serious mental, emotional, social or even financial harm may justify forced hospitalization. Some Canadian jurisdictions have also gone beyond dangerousness as the sole justification for involuntary admission. For instance, in British Columbia, Saskatchewan, Manitoba and, to a lesser extent, Ontario, a mentally ill person may be involuntarily admitted to prevent substantial mental or physical deterioration (McLachlin 2005, 21).

### The Starson Case:

Briefly stated, Scott Schutzman was an individual who legally changed his name to Scott Starson in 1993 (because he believed he was the son of the stars) and preferred to be called Professor Starson. He had a history of mental illness dating back to 1985. He was diagnosed as having bipolar disaffective disorder and, over the years, had an estimated fifteen hospitalizations both in Canada and the United States. He graduated from Ryerson Polytechnic University with a degree in electronic engineering and worked at several jobs including a sales job with an instrumentation company. However, his intellectual interest was physics and he developed several significant connections in the academic community as well as writing several scientific papers. He co-authored a refereed

journal article with Pierre Noyes, director of the Linear Accelerator Centre at Stanford University in California, who described Starson as being ten years ahead of his time (Tyler 2003). However, Starson has not published since 1995.

Starson had a run-in with the Toronto police in 1998 and was charged with uttering death threats to several of his neighbours in the apartment building where he resided. In November of that year, he was found not criminally responsible on account of mental disorder (NCRMD) and in January 1999, the Ontario Review Board (ORB) ordered him detained for twelve months at the Centre for Addiction and Mental Health (CAMH) in Toronto. Two psychiatrists (Dr. Ian Swayze and Dr. Paul Posner) at the CAMH prescribed a combination of mood stabilizers and anti-psychotic medications for Professor Starson but he refused treatment. On 20 January 1999, the Consent and Capacity Board (CCB) concluded that Starson was almost in complete denial of his mental illness and was not capable of making his own decisions about treatment. The Board also concluded that it was in his "best interest" to take medication. The phrase "best interest" would prove to be significant as the case unfolded.

The legal test for determining whether a person is capable of making his or her own treatment decision is found in section 4(1) of the Health Care Consent Act, 1996 (HCCA). It is a two-part test. Under this section, a person is "capable with respect to treatment" only if:

1. the person is able to understand the information that is relevant to making a decision about the treatment; and
2. the person is able to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

The HCCA allows CCB decisions to be appealed, which Starson did, and the case came before Madam Justice Molloy of the Ontario Superior Court. It is important to note that s. 4 of the Act presumes that people are capable; therefore, the onus is on the appellants to demonstrate that a person is incapable. On 26 November 1999, Molloy concluded that the Board's finding was unreasonable and set it aside. In her view, the psychiatrists did not offer any compelling evidence that any of the drugs previously administered to Starson had ever been effective. She also claimed that the Board's conclusion that Starson completely denied his mental condition was a "fundamental error." Moreover, according to the legal decision, the CCB did not confine itself to the legal tests and made a subjective determination relating to the "best interest" of the individual which was beyond the scope of the CCB.

Drs. Posner and Swayze appealed Judge Molloy's decision on the grounds that she misapplied both the standard of review and the statutory test in section 4 (1). Once again, the Ontario Court of Appeal, by a vote of 3-0 upheld the lower court's finding that Starson was capable of making a decision regarding his treatment. According to their decision, the Court found that Starson did acknowledge that he had mental health issues and found that his reason for refusing treatment - a reduction of his cognitive abilities - was a reasonable ground on which to refuse treatment. In addition, the psychiatrists could not guarantee that the proposed medication regimen would be effective. Subsequently in the Supreme Court case, the *Amicus Curiae* stated that the Court of Appeal's decision was important because it "sent a message to

psychiatric boards that they can't always take a 'paternalistic' approach to patient treatment" (Tyler 2003). At the same time, family based organizations such as the Schizophrenia Society of Canada and its provincial arms were not happy with the decision. Starson's mother was devastated by the Court of Appeal's decision.

You know what the problem is? They didn't include me. [My] son is a man of great potential suffering without treatment. He thinks he's superman. He thinks he is the most brilliant person in the world. I adore my son, the man that is my son. He is truly such a good-natured, gentle, fascinating, beautiful person, but his illness has destroyed me. It's been devastating (Tyler 2003).

By the end of 2000, Starson was transferred to maximum security at Penetanguishene. After another hearing, the Ontario Review Board (ORB) concluded:

While there is no evidence that Starson has been physically assaultive during his time in this facility, his ongoing barrage of death threats, insults and pending torture constitute potential psychological harm. To subject co-patients, whether in this facility or a less secure co-educational setting, to this kind of versatile flurry of assaultive behaviour is unwarranted. To allow Starson to suffer the consequence of an untreated mental disorder is likewise unwarranted (Spencer, [www.mdcanada.ca](http://www.mdcanada.ca): 22 October 2003)

It is interesting to note that this conclusion was made after Justice Molloy had ruled that Starson was capable of deciding whether or not to accept treatment. Many within the psychiatric community saw the last sentence as a parting shot at Justice Molloy's decision. At the Penetanguishene facility, Starson continued to refuse treatment. Once again, a psychiatrist - Dr. Russel Fleming - appealed the decision of the Ontario Court of Appeal to the Supreme Court of Canada which heard the case in 2002 and delivered its decision on 6 June 2003. It is important to note that there were several intervenors in this case. Intervenors providing information and support for the appellant (Dr. Fleming) were the Centre for Addiction and Mental Health (CAMH) and the Schizophrenia Society of Canada - a family-based, non-profit federation organization that has provincial offices and local chapters. Intervenors that provided support for the respondent (Starson) were two pro-consumer groups - the Mental Health Legal Committee and the Mental Health Legal Advocacy Coalition.

Although the Starson case did not revolve around equality rights of the Charter, it was a case that galvanized the psychiatric community and pitted one individual and two consumer-based organizations against psychiatrists and several family-based organizations. As it relates to consumer-based groups, the Mental Health Legal Committee (MHLAC) is an organization of lawyers and community legal workers who represent consumers of mental health services. It was formed in 1997, and a number of its members appear regularly before the Consent and Capacity Board, among other agencies. The Mental Health Legal Advocacy Coalition (MHLAC), on the other hand, is a group of lay advocates in the field of mental health law. For the most part, its members self-identify as consumers/survivors of mental health services. Both of these groups supported the decisions made by the two lower courts in the Starson case and argued that the Board not only misapprehended the evidence but also misapplied the test for capacity. As such, these groups

claimed that its decision was unreasonable in fact and incorrect in law (MHLC and MHLAC, 2002: 2). These groups argued that by basing its decision on the concept of 'best interests,' the Board erred in applying the test for capacity. According to their factum: "it presupposes the existence of universally accepted values respecting human endeavour and mental wellness. It shuns diversity and, ultimately, incites paternalism" (MHLC and MHLAC, 2002: 3).

In the opinion of MHLC and MHLAC, capable individuals have the right to take risks and are presumed free to make decisions that are considered unreasonable. They pointed to the decision made in an earlier case involving the CCB when the Honourable Mr. Justice Harris stated: [i]t is mental capacity, not wisdom, that is at issue here. The appellant...carries with her, like all citizens, the right to be wrong" (MHLC and MHLAC, 2002: 4). They also pointed to the decision in the Fleming v. Reid case as reaffirming the right to refuse treatment under the Charter.

Mentally ill persons are not to be stigmatized because of the nature of their illness or disability; nor should they be treated as persons of lesser status or dignity. Their right to personal autonomy and self-determination is no less significant, and is entitled to no less protection than that of competent persons suffering from physical ailments (MHLC and MHLAC, 2002: 4).

Although these pro-consumer intervenors presented the results of two studies that were quite critical of anti-psychotic drugs and acknowledged that there are some side effects associated with these medications, it is important to note that there are many research studies that point to a significant correlation between medication non-compliance and an increased risk of re-hospitalization, emergency room visits, symptom exacerbation and homelessness. In addition, many within the psychiatric community, the medical community, community-based mental health facilities and family educators, among other interests, are solidly within the camp of the treatment model.

### Supreme Court Decision:

In a split 6-3 decision, the Supreme Court of Canada upheld the lower courts' decisions and ruled that Starson did have the capability and capacity to determine his own treatment. Writing for the majority, Supreme Court Justice Major wrote:

Although the patient did not conceive of the condition as an illness, he was quite aware that his brain did not function normally. There was also no evidence that the proposed medication was likely to ameliorate the respondent's condition...The Board's conclusion that treatment would improve his chances at future review board hearings is entirely speculative (Starson v Swayze, 2003).

Justice Major believed that the legislative mandate of Ontario's Consent and Capacity Board was to adjudicate solely upon a patient's capacity. The Board's conception of the patient's 'best interests' was irrelevant to that determination (Starson v Swayze, 2003: para76). Therefore, like the lower courts before it, the Supreme Court took a highly legalistic position in admonishing the CCB

for overstepping their jurisdiction and role. Even if someone was making an unwise choice, this was their right. Justice Major stated: "The right knowingly to be foolish is not unimportant; the right to voluntarily assume risks is to be respected. The State has no business meddling with either. The dignity of the individual is at stake" (Starson v Swayze, 2003: para76).

Drawing on the work and research of D.N. Weisstub, Justice Major justified his decision by pointing to an historical failure to respect this presumption.

The tendency to conflate mental illness with lack of capacity, occurs to an even greater extent when involuntary commitment is involved, has deep historical roots, and even though changes have occurred in the law over the past twenty years, attitudes and beliefs have been slow to change. For this reason it is particularly important that autonomy and self determination be given priority when assessing individuals in this group (Weisstub, 1990: 16).

In the dissenting opinion rendered by Madam Chief Justice Beverly McLachlin, she concluded that the issue of determining capacity involves walking a fine line in balancing values.

The [Health Care Consent Act] confronts the difficult problem of when a mentally ill person may refuse treatment. The problem is difficult because it sets in opposition fundamental values which we hold dear. The first is the value of autonomy - the ability of each person to control his or her body and consequently, to decide what medical treatment he or she will receive. The second value is effective medical treatment - that people who are ill should receive treatment and that illness itself should not deprive an individual of the ability to live a full and complete life. A third value - societal protection - comes into play in some cases of mental illness. Where the mentally ill person poses a threat of injury to other people or to him or herself, it may be justified to impose hospitalization on the basis that this is necessary in the interests of public safety which permits courts and Boards to impose hospitalization on an accused person found not criminally responsible on account of mental disorder (Starson v Swayze, 2003: para 6).

Unlike the lower courts and the majority of the Supreme Court, the dissenting opinion concluded that the Board had not erred in its judgement. It reasoned that the absence of understanding and acknowledgement of his condition rendered Scott Starson unable to understand the factors relevant to making a decision about treatment. In addition, he was considered 'unable' to appreciate the consequences of lack of treatment. Far from being an error, the Board followed the accepted approach to ascertaining ability. As for the Board's preliminary expression of sympathy of concern when it invoked the language of medication compliance being in the patient's 'best interests' - this did not mean (in McLachlin's view) "that the Board focussed on the wisdom of refusing treatment rather than on Professor Starson's capacity" (Starson v Swayze, 2003: para 22).

The decision by the Supreme Court was highly controversial. On

one hand, survivor and consumer groups lauded the decision as a victory. Other groups such as the Schizophrenia Society of Canada lamented the decision claiming that the rights of families to have their loved ones treated for serious mental illnesses had been disregarded by the courts. Immediately after the decision, Starson's mother issued the following statement: "How can the Supreme Court hope to rule on a human being without having seen the person himself; without really and truly understanding the effects of his illness on his family and his society? It's beyond me" (Makin: 7 June 2003). Perhaps, though, the largest criticism came from the Canadian psychiatric community. Their concerns relate to the narrow legalistic view taken by the judges in assessing treatment decisions affecting the mentally ill. The purpose of the HCCA, they argued, is not to deprive people of their civil rights but rather to help people to get treatment when they are not able to make decisions on their own. As a result of this decision, mental health practitioners have suggested that the Health Care Consent Act should be amended to allow the Consent and Capacity Board to take a patient's "best interests" into account. The 'best interests' test is the one used in British Columbia, Saskatchewan and Newfoundland and, according to Gray et al, there have been no reported court cases in those jurisdictions that have challenged the authority of provincial boards. Another concern relates to the effectiveness of medication. How will the courts balance the opinions of psychiatrists - many of whom have their research supported by pharmaceutical companies - with the opinions of consumers and with the opinions of family members and the groups that represent their interests? As noted by Christina Spencer:

Doctors must make sure they lay out their case for incapacity - if they have one. They can no longer talk to the consent board in shorthand. Before Starson, the practical standard for the physician was merely, in Anita Szigeti's words, "that they had to show up." Now, more questions are being asked at consent hearings. Starson has probably helped future psychiatric patients (Spencer, mdcanada.ca: 22 October 2003).

In a number of legal post-mortems of the Starson decision, the fact that the Supreme Court did not rule that Starson's incapacity on the denial of his illness violated "principles of fundamental justice" within the meaning of Section 7 of the Charter has potentially opened the door to a future Charter challenge. In particular, in both the majority and minority opinions of the Starson case, reference was made to the capable patient's right as "fundamental" to his or her "dignity, autonomy and right to self-determination" - language that strongly suggests a positive decision by the Court under Section 7 of the Charter" (Sklar 2007, 394).

## Conclusions:

In many respects, the Starson decision reaffirmed the trend that individual rights of the mentally ill are being championed by the courts in the post-Charter era. However, as it relates to the rights of other interests in the area of mental health, the courts have found only a delicate balance. Family-based mental health advocacy groups, organizations such as the Schizophrenia Society of Canada and its provincial affiliates as well as the Mood Disorders Association are all attempting to ensure that families need to be treated as partners in the care of their family members. The language of

the final report of the Special Senate Committee on Social Affairs, Science and Technology clearly supports the claim that families must be considered as partners in Canada's mental health system. Families of individuals who refuse treatment are increasingly being forced to navigate a complex psychiatric and legal system in efforts to demonstrate that their family members are not capable of making treatment decisions. Although most mentally ill persons are not violent, there may be instances when they may present a significant risk of harm to themselves or others. In this important area, they may be a risk to public safety and may become mired in the criminal justice system. In the end, communities are picking up the costs for the long-term institutionalization of individuals where outcomes for recovery are reduced, not enhanced.

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