

# **Representatives, Informed Consent and Psychiatric Rights: Participatory Action Research by Psychiatric Patients in Vancouver, BC**

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## **Abstract**

*Michel Foucault in an interview in his book, Power/Knowledge, said “A new mode of the ‘connection between theory and practice’ has been established. Intellectuals have got used to working, not just in the modality of the ‘universal’, the ‘exemplary’, the ‘just-and-true-for-all’, but within specific sectors, at the precise points where their own conditions of life or work situate them (housing, the hospital, the asylum, the laboratory, the university, family relations and sexual relations).” (Foucault, p. 126) This statement may serve as a foundation for the efforts of an academic researcher, a social service worker, and an administrator, all who have been treated in the psychiatric system and who formed a working group within the West Coast Mental Health Network. They have conducted focus groups around the question of representation agreements for psychiatric patients who currently lack the right of informed consent to treatment.*

## **Introduction**

The Representation Agreement Act Working Group of the West Coast Mental Health Network was seeking legal reform intended to increase the self-determination of all psychiatric patients in 2011-2012. Choice in treatment decisions, including a choice not to be treated, is a fundamental value for many individuals who have been through the psychiatric system in Canada, if not in the world as well. The World Network of Users and Survivors of Psychiatry embodies this value in declaring that it is “...dedicated to protecting the human rights, self-determination and dignity of all user/survivors throughout the world.” (WNUSP, 2012)

A central ethical principle of social work is the pursuit of social justice (CASW Code of Ethics). Practice is not merely brokering resources for marginalized individuals, providing services such as supportive housing, counselling, financial support and quality of life opportunities or acting as agents of the state in the family law and criminal justice systems. It is also engagement in advocacy and political change aimed at combating inequality and oppression. In his essay, *Anti-oppressive Practice in Mental Health*, Grant Larson prescribes that “...practitioners become active participants in social action and reform.” Among social action options he lists is “...actively pursuing changes in legislation and public policies that disenfranchise those with disabling conditions of mental health” (Larson, p. 52).

## The Problem

At a West Coast Mental Health Network board meeting in 2010 the working group identified the repeal of section 11 of the Representation Agreement Act of B.C. as a desired change in the province's mental health legislation

In British Columbia's state-based model of treatment decision-making for involuntary psychiatric patients typically an employee of the state is mandated through legislation to make the patient's treatment decisions (Gray, p. 202). This employee is a physician, usually a psychiatrist. John Gray identifies the alternative to this model as a private treatment decision-making model. In a private model of treatment decision-making for involuntary psychiatric patients a substitute decision-maker (SDM) is mandated to make the treatment decision, based on the advice of a physician, according to the principles of informed consent. (Gray, p. 455). The SDM is often a member of the patient's family, but might also be a legally appointed representative.

The legal reform sought by the working group is the establishment of the right of a legal representative, who may be designated as a primary substitute decision-maker, to participate in treatment decisions on behalf of a patient who may be deemed legally incapable. The powers of the representative would include the right to refuse consent to treatment on behalf of the patient who appointed her as well as the selection of alternative treatments proposed by the treating physician. This reform represents an unbinding of the power currently concentrated in the hands of the psychiatrist or in other words the empowerment of the patient and civil society (represented by substitute decision-makers) with respect to the power of the state. It is a democratic reform in that the capability to make decisions of intimate relevance to individuals may be returned to those individuals who were the subject of decisions that have been made up to this point by a medical bureaucracy.

The psychiatrist's relationship with her patient is all at once humanitarian (or caring), legal, clinical, customary and expeditious. In the involuntary admission to a psychiatric facility the element of emergency is often present. The patient has lost a measure of reason and self-control in bi-polar and schizophrenic cases especially and is at a putative risk of harming herself or others and of deteriorating to a point where a personal disaster in life threatens poverty, paranoia, delusions, hallucinations, harm, poor health and problematic social relations. The psychiatrist in BC has been tasked with the sole responsibility for the patient's treatment and decisions around that treatment. The question arises whether this bureaucratic concentration of responsibility is sufficiently respectful of the human rights of the patient and, moreover, whether it is actually the most effective configuration of therapeutic power with respect to personal outcomes for the patient and social outcomes for the community.

The Representation Agreement Act is a piece of personal planning legislation. It provides for a resident of B.C. to appoint a legal representative who may make decisions on her behalf when that person is deemed legally incapable. At present the Act empowers the representative to make decisions regarding personal affairs such as finances, housing and health care in cases of incapacity. The powers of the Act are available to every resident of British Columbia with one exception. The exception is found in section 11 of the Act, which reads:

- (1) Despite sections 7 (1) (c) and 9, an adult may not authorize a representative to refuse consent to
  - (a) the adult's admission to a designated facility under section 22, 28, 29, 30 or 42 of the *Mental Health Act*,
  - (b) the provision of professional services, care or treatment under the *Mental Health Act* if the adult is detained in a designated facility under section 22, 28, 29, 30 or 42 of that Act, or
  - (c) the provision of professional services, care or treatment under the *Mental Health Act* if the adult is released on leave or transferred to an approved home under section 37 or 38 of that Act.
- (2) A representative must not consent to the provision of professional services, care or treatment to the adult for the purposes of sterilization for non-therapeutic purposes. (BC Revised Statutes)

Although striking down section 11 would seem to open the way to more decision-making power for psychiatric patients who are involuntarily detained, other stumbling blocks remain. Primary among them is the current proscription of substitute decision-makers acting in regard to involuntary psychiatric treatment found in section 2 of the Health Care (Consent) and Care Facilities (Admissions) Act of B.C. The Act provides for the right to informed consent in medical treatment for all residents of BC. The only exception to this right is found in section 2. It reads as follows:

2. This Act does not apply to
  - (a) the admission of a person to a designated facility under section 22, 28, 29, 30 or 42 of the *Mental Health Act*,
  - (b) the provision of psychiatric care or treatment to a person detained in or through a designated facility under section 22, 28, 29, 30 or 42 of the *Mental Health Act*,
  - (c) the provision of psychiatric care or treatment under the *Mental Health Act* to a person released on leave or transferred to an approved home under section 37 or 38 of the *Mental Health Act*, or
  - (d) the provision of professional services, care or treatment to a person for the purposes of sterilization for non-therapeutic reasons. (BC Revised Statutes)

By way of explanation, sections 22, 28, 29 and 30 all relate to rules regarding involuntary admissions to a psychiatric facility. Sections 37 and 38 likewise refer to a condition where informed consent is denied but the patient is living outside the psychiatric facility on “extended leave” or community treatment order (CTO) as it is known in other jurisdictions. Finally, section 42 refers to transfers of an already committed patient from another province. In fact, in all the sections of the Mental Health Act of BC listed and referred to as exceptions in section 11 of the Representation Agreement Act and section 2 of the Health Care Consent and Care Facilities Act, those being sections 22, 28, 29, 30, 37, 38 and 42, the patient is implicitly denied the right of

informed consent and any kind of choice with respect to the psychiatric treatment she is receiving. Her self-determination as a human being is completely stripped away.

The first step in returning that right of self-determination is returning the right to informed consent of psychiatric treatment denied psychiatric patients under section 2 of the Health Care Consent and Care Facilities Admission Act.

The elements of informed consent are laid out in section 6, ss. e) and f) of that Act. The subsections read as follows:

- (e) the health care provider gives the adult the information a reasonable person would require to understand the proposed health care and to make a decision, including information about
  - (i) the condition for which the health care is proposed,
  - (ii) the nature of the proposed health care,
  - (iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and
  - (iv) alternative courses of health care, and
- (f) the adult has an opportunity to ask questions and receive answers about the proposed health care. (BC Revised Statutes)

Further entrenching the power of the psychiatrist with respect to treatment decision-making is the following section 8(a) of the Mental Health Act, which reads:

- 8. A director must ensure
  - (a) that each patient admitted to the designated facility is provided with professional service, care and treatment appropriate to the patient's condition and appropriate to the function of the designated facility and, for those purposes, a director may sign consent to treatment forms for a patient detained under section 22, 28, 29, 30 or 42. (BC Revised Statutes)

In addition to this power to sign for the patient's consent in section 8 of the Mental Health Act is the legal fiction of "deemed consent" embodied in section 31, ss. (1) of the Mental Health Act. It reads as follows:

- (1) If a patient is detained in a designated facility under section 22, 28, 29, 30 or 42 or is released on leave or is transferred to an approved home under section 37 or 38, treatment authorized by the director is deemed to be given with the consent of the patient. (BC Revised Statutes)

These selections of legislation are indications, though not exhaustive, of the barriers that psychiatric patients face in the pursuit of their human rights, their self-determination and their dignity. The legislation is also indicative not simply of discrimination against people with diagnoses of mental illness but of a radical state of exception within what Agamben has called the bio-political State. The State, in seeking to ensure the health of its constituency is able at the same time to section off a sub-population from its political rights. (Agamben, 1998) While this prospect may seem

ominous enough, the day-to-day reality for incarcerated individual psychiatric patients can be exasperating in the extreme if not at times terrifying.

### **History of Activism**

The West Coast Mental Health Network, a consumer/survivor run mental health agency, is committed to maximizing the well-being of those who have been diagnosed with a psychiatric disorder. In the past, among many other activities including self-help groups and a quarterly newsletter, this has involved research efforts aimed at identifying ex-patient complaints about the mental health system in BC [Voices of Experience, 1993], exploring therapies of choice for women ex-patients [Hearing Women's Voices, 1998], and developing a psychiatric women's safe house [What Women Want, 2002]. The recent position paper based on data from focus groups organized by the West Coast Mental Health Network was concerned with changes to the Representation Agreement Act [WCMHN, 2011] and was the latest of the Network's efforts at fulfilling its mandate to support the well-being of its members and constituency. The research documented in this report expands upon the above-mentioned position paper and seeks to disseminate the positive gain achieved through the conduct of the two focus groups held in 2011.

### **Prelude to the Research**

The focus groups mentioned above have been the central gain in the pursuit of change on the part of the working group. They took place following a process that began in 2005. The Network Coordinator at that time responded to a call for suggested changes to the Representation Agreement Act put forward by the Attorney General of BC. The Network response asked for a change to the Act that would allow involuntarily committed psychiatric patients to make use of a legally appointed representative in their psychiatric treatment, in short, the repeal of section 11 of the Act. Receiving no reply from the Attorney General regarding this response, the author of this report, then Coordinator of the Network, and another board member of the Network, composed a collaborative position paper on the Representation Agreement Act in 2006. That position paper was posted on the Network's website, but without supportive partners to encourage the venture and share the workload, further effort was abandoned for some years until revived at a board meeting of the West Coast Mental Health Network in 2010.

At that 2010 board meeting, the two other members of the working group and the author agreed to take on some of the work involved in continued systemic advocacy. The meeting drafted a resolution for the approaching annual general meeting of the Network. The resolution, which sought the support of the Network membership for a drive to make the Representation Agreement useful for psychiatric patients, was endorsed at the general meeting in September 2010 and with that mandate, the current Coordinator of the Network solicited help from community legal resources.

The working group met with representatives from PIVOT Legal Society and the British Columbia Civil Liberties Association (BCCLA) consecutively in February 2011, outlining to them the mandate given by the Network membership and the rationale for seeking to change the exclusion of involuntarily committed psychiatric patients contained

in the Representation Agreement Act. None of the working group having specifically legal training, the importance of the Health Care Consent Act of BC in underpinning the quest for the right to informed consent in psychiatric treatment decisions remained obscure at that time.

A BCCLA representative suggested at a meeting with the working group that a position paper based on the voices of Network members be composed and returned to the BCCLA, which at that time was at work on its own position paper pursuing legal reform of legislation affecting involuntarily committed psychiatric patients. It was hoped the Network's position paper might support or inform the BCCLA paper that was in progress. The working group, after some discussion, decided upon focus groups as the means to create its position paper and solicited interested participants through an email to the Network general membership numbering upward of 600 members at the time. This set the stage for an exercise in participatory action research, which sought to generate evidence with a view to social change.

### **Method**

Out of a membership of nearly 600 ten Network members responded to the emailed solicitation for participation in the focus groups. All ten attended the focus groups along with the three members of the working group, themselves ex-psychiatric patients and participants in the focus groups. The focus groups were held in cost-free rooms at the Gathering Place, a community centre for street involved adults and youth in downtown Vancouver. Consisting of current and ex-psychiatric patients these focus groups held in April of 2011 addressed the question in principle of whether an alternative decision-making model for involuntary psychiatric patients was desirable, although formally a single central research question was not explicit. Rather a set of a dozen questions noted below was used to elicit discussion. The questions were posed to the groups in the order noted below.

The two focus groups, the first on April 5, 2011 and the second on April 15, 2011 produced a total of nearly three and a half hours of discussion recorded on a digital audio recorder. The audio recordings were then transcribed producing two documents with approximately 25,400 words in total. The transcripts' data was grouped into themes from which individual data were extracted for this paper according to criteria of intelligibility, grammatical coherence, representativeness of the diversity of views and stories told and the avoidance of duplication.

It had been intended that the focus groups would be about the value of repealing section 11 of the Representation Agreement Act of B.C. However, participants in the focus groups had interesting things to say that went beyond mere discussion of a change in legislation.

### **Research Questions**

1. Have you been confined to a locked room against your will? If so, was a family member or friend informed? Was anyone allowed to visit while you were in confinement?

2. Have you been given psychiatric medications without your consent? Were you informed in advance of any adverse effects of the medications? Were the reasons for treatment explained to a family member or friend?
3. What side effects did you experience from psychiatric medications, and how did that affect your ability to function after you left the hospital?
4. What was your experience after leaving the psychiatric ward? Did you have to follow certain terms and conditions to avoid being re-incarcerated, and if so, how did that affect you? What additional support (or care) would have benefited you?
5. Have you ever withheld information from a psychiatrist or other mental health worker about your thoughts, symptoms or condition out of fear of treatment? If you were able to appoint a representative (who could refuse consent to treatment on your behalf), would you be more willing to disclose information?
6. What alternatives to treatment do you think the mental health system needs? Do you have any recommendations for short-term (crises) as opposed to long-term alternatives?
7. Reflecting on your experiences of being involuntarily committed, would you have benefited from having a representative to interact with mental health care professionals on your behalf?
8. If you were able to appoint a representative to make important treatment decisions on your behalf, whom would you appoint and why? (No names needed, just their relationship to you)
9. Do you have a clear idea of the kind of instructions you would give to your representative?
10. How would it be different for you if you knew you had a representative for those times of crisis when doctors might not listen to you?
11. Why is it important to have a representative?

### **Focus Group Data and Analysis**

Several themes emerged in the data of the focus groups that were not included in the position paper tendered to the BCCLA. This was because the position paper's emphasis was on supporting changes to section 11 of the Representation Agreement Act of BC. The perspectives and stories expressed in the focus groups went far beyond the confines of the purposes of the position paper. They comprise a narrative of experiences in the hidden corners of the province and often contradict the sunny and whitewashed

presentations of the mental health system disseminated by government and its health agencies. In this sense they are what have been identified as “subjugated knowledges.” (Foucault, p. 81)

## **Abuse**

Foremost among the stories in the focus groups were stories of abuse. The extremity of treatment such as long stays in isolation and excessive use of force are not uncommon and give evidence of callousness on the part of hospital staff. Whether as a result of policy, staff burn-out or poor practice it is not clear what makes staff treat patients so brutally, but in the caring professions lapses of this kind are unacceptable to the participants of the focus groups and by implication many others.

One participant related the following: “...They strapped me to a rolling stretcher and they left me there for hours including after I was wheeled into the jail cell area that I just described.” Another participant recalled a similar experience: “I was strapped down on a bed in restraints for eight hours at VGH.... And when I got out my hands were bruised and I was really upset.”

The use of force in situations such as are described raises the question of why force is necessary. Some participants describe how despite trying to be reasonable force was used in any case. One participant described an emergency room encounter with hospital staff. “And since I got in there in the emergency part I said ‘I’m not staying in here. I don’t need to be in here.’ And they started being heavy-handed with me right then....”

Another participant describes his astonishment at the peremptory use of force against him. “I too had been restrained on a bed. I can’t say that I’ve been confined in a locked room against my will. But also at VGH for me I felt like I was being treated like somebody who had committed a major, major crime. And all I had asked was for one or two simple requests.” The same participant went on. “If a person gets violent, perhaps, but just asking simple questions does not in any way, shape or form be [sic] justified by being locked down to a stretcher.”

Another participant described her consternation at how she was treated. “And I’ve also been locked up at UBC in a room part-way through my stay and it wasn’t really very obvious why.”

Patients frequently do not understand why they are being treated the way they are. One participant simply said the following. “They gave me drugs against my will.” This was related to the group as a complaint indicating the unpreparedness of patients for the loss of their right to self-determination. Similarly unprepared was another participant who could not understand the motives of hospital staff relating to her arrival at hospital. “I must have been questioned maybe thirty times throughout my hospitalization about how come I was brought in by the police.”

Forced injections are also a bone of contention among the complaints of participants. The impression arises from the focus groups that in our security conscious society excess in the use of force is easily overlooked despite the system in British Columbia being ostensibly committed to the use of the least restrictive means of treatment. “One of the things that’s particularly objectionable is getting injected. And



I've been injected unnecessarily a number of times. And being injected in the hospital environment involves a whole bunch of security being called, up to five people, and being held down and being exposed. It's just a horrible, horrible process." Another participant supported the view that excessively restrictive means were being used. "And if you're going to be injected, if you're going to have to be tied up – not tied up, but it's almost like being in shackles – whatever they do to you, you know...."

Finally, the use of force is embodied in seclusion. One participant described excessive confinement. "I've been locked up in rooms against my will for, like, days on end without being let out, without any lights coming on." Another participant's description of excess was likewise astounding. "I will say in more detail which is that I, at various times when I have been confined to locked rooms I've also been, as most people are, heavily drugged, and often been in restraints at the same time, which is triple-redundancy par excellence."

## **Fear**

The experience of abuse has one overriding effect and that is fear. And it is not fanciful to suggest that the use of fear to control patients is a primary tool in the hands of staff on psychiatric wards. One participant had this to say: "Because I've known that electro-shock, or electro-convulsive therapy as it's called, is a possibility, I've often been absolutely terrified on psychiatric wards, which is very harmful. And it is seen to be clearly there as a threat. 'If you do not comply with other forms of treatment then that is a step that we reserve the right to impose on you.'"

Another participant voiced how having a representative would reduce the fear she experienced in hospital. "...just having that [a representative] would really, really reduce my anxiety and my fear and give me a little bit of control or, as you said, autonomy back." Another participant expressed similar thoughts: "...knowing that there was somebody else there, there would have been less fear, I would have felt less alone, I would have felt more hope and that kind of stuff." Another participant spoke about disclosure to the hospital staff: "I have definitely withheld information out of fear of being hospitalized and also fear of having ECT [Electro-Convulsive Therapy] forced on me...."

Again, these stories were excluded from the position paper the focus groups were conducted to produce. But they are a trenchant indictment of the way our psychiatric facilities are run and the need for greater self-determination for patients so that they are not "terrified" when they are receiving psychiatric treatment.

## **Trust**

Needless to say, experiences such as those related above cut to the heart of the relationship between patient and psychiatrist. Mistrust of psychiatrists was also thematic within the focus group data. One participant said flatly, "I don't trust psychiatrists. I think they're trained to judge and control and they by definition cannot be of assistance to me because of the way the legislation works." Another disclosed that, "...I definitely have withheld information and it was certainly out of fear of treatment...."

Responding to a question about how the presence of a representative would affect disclosure of personal information to a psychiatrist one participant said, “Yeah, I think that it might affect my openness.”

A participant summed up his own strategy when involuntarily committed. “...I think it’s very prudent not to disclose a lot of things to psychiatrists about your thoughts and emotions, because when it come to thoughts and emotions and the interior life of an individual psychiatry is somewhat predatory.”

Clearly, when individuals are treated against their will and are not prepared for the loss of their power of choice, the psychiatrist is blamed as she is at the top of the pyramid of oppression that weighs down upon the psychiatric patient. And when a system claims to be helping people and goes on to harm them through coercion, trust in the system and in psychiatrists can only fail.

### **Side Effects**

One of the stumbling blocks which trust in psychiatrists encounters is the problem of side effects of prescribed medication. One participant expressed the problem she faced “...every time I was hospitalized I was not explained what the side effects were, what I was given, what it was for and the last time on September 28 my meds had been increased to the point where I had trouble walking.”

Another expressed her frustration this way: “So, they do not talk about adverse effects at all. I have to drag any discussion of that out of them.” Another participant gave this graphic description: “...It started with, like, an intense form of tiredness and I was actually hallucinating and then my brain was racing and my neck and my spine were literally twisting like a pretzel and it was just like, so gruesome and horrible you wouldn’t wish it on Hitler.”

Changes in personality were described: “And the medication they gave me, my parents-in-law saw how it took away all my personality. I couldn’t function properly so my mother-in-law said, ‘Stop taking that. Just don’t take that anymore.’”

Another participant described the debilitating effects of some medications. “So, here I was on a new medication, far too high dosage to begin with. And if it had not been substantially reduced, which thankfully it was, I could have ended up probably operating in the terms of being a vegetable.”

“I’ve had, like, Parkinsonian-like symptoms of stiffening of muscles, leaning, loss of balance,” said one participant. “I’ve had very rare forms of seizures that lasted like two weeks at a time.”

The responsiveness of hospital staff to complaints of side effects also came under fire. “And so, it’s like, they do not care about the side-effects because they just keep going back to, you know, ‘Yes, but – if it weren’t for the positive effects of healing the symptoms or of treating the symptoms....’”

Another frightening description of side effects was this. “But on the subject of Haldol, I’ve been given Haldol a few times and had among other side effects lock-jaw was the really atrocious one, also foaming at the mouth.”

## **Family**

In contrast to the current promotion of family involvement in the recovery of psychiatric patients members of our focus groups expressed strong opposition to the involvement of family members, citing bad experiences with them where family appeared to turn against the patient and the doctor's opinions were privileged.

One participant explained, "My parents believed what the medical profession had to say and wanted me to take it. Which is why they wouldn't be my representatives if I wanted a representative."

Another participant put it this way. "...My family members are of the opinion that because these doctors and psychiatrists are specialists that they must know what they're doing." The same participant said later, "I personally would not get any of my immediate family as a representative. They are of the opinion that the specialists know what they're doing. And I'm appalled by that."

A third participant said, "...You know, at this point I don't know if I would trust anybody to represent me. That includes my sister, my daughter, who did come and were in a family session with me." The same participant said later of her family members, "...I felt like I was ganged up on, that they were in collusion. And I questioned their loyalty."

Another participant said about the absence of family involvement with the West Coast Mental Health Network, "It would be really nice to see that continue in the future, I mean, that we're not, that we are member-run and driven and that we don't let family come in.... If I knew that they could have any involvement in this organization I wouldn't want to have anything to do with it."

## **Anonymity**

Psychiatrists in urban and many rural settings have never met their patients prior to their first encounter on an emergency ward or in an office. In essence, they are strangers to the patient. In a context where knowledge of behaviour, be it unusual or typical, is crucial in coming to diagnoses and prescribing treatment, having someone who knows the patient involved in treatment decisions seems to make a lot of sense.

One participant said the following. "And the reason that I got out earlier is that I have a regular psychiatrist that I see and he knows me. And he was able to talk to the psychiatrist in the hospital and convince the psychiatrist in the hospital that I was at baseline, cause that psychiatrist didn't know me from Adam, and he had no idea what baseline looked like, so he was just going to keep holding me and keep drugging me to be sure."

Another participant had this to say, "And if you're going to be injected, if you're going to have to be tied up – not tied up, but it's almost like being in shackles – whatever they do to you, you know, there should be someone there to help you out and to say, 'Well, no. She doesn't need this or he doesn't need this or why not do this instead,' you know, there's got to be a more humane way."

Comments like these support the use of substitute decision-makers, such as friends or legal representatives.

## **Power**

As is so often the case with concentrated power, responsiveness to the particular life situations of patients is very poor. Participants were very clear that they felt psychiatrists were not responsive to their needs and wishes. As one participant described the psychiatric system, "...it's a power structure." Power was uppermost on the minds of many participants because they had been subject to what felt like arbitrary power. Said one participant, "And I just feel like I'm hitting a brick wall any time I try and say, 'I don't want to be on this medication.'"

Another participant felt as if painful sanctions were being applied to her. "The conditions were...that I had to follow the medical plan in terms of medication. And it was explained to me that if I didn't, I would be certified again. In fact, the police would pick me up. That was the threat."

One participant emphatically registered her complaints. "Restraint, restraint, seclusion, ECT, overmedication and just being listened to about what kinds of things in the environment are triggering me, rather than saying that my behaviour is the problem. Like what in the environment is affecting my behaviour?" She continued by describing what she would want a representative to do. "Things around my behaviour I would make clear instructions. I don't know exactly what the details right now around that. But very important around behaviour 'cause they're basically into social control is how it goes to me so...behaviour control, you know, or social control."

The role of a representative as a defence against power was a common theme of the focus groups. "I think it's really important to have a representative so that, one, you can't be coerced against your own wishes...to have already set them out beforehand and I think what other people said earlier, too, that this whole idea that your not one person up against the psychiatric establishment or something like that...that you have somebody on your side who's there with your wishes and can advocate on your behalf."

Being up against a large bureaucracy was an experience common to patient committals. "I think the typical situation is you feel like you just get lost in the system. You're powerless, you're bewildered and a number of other feelings, a myriad of feelings."

## **Rights**

One participant made a very incisive comment that was supported by several participants in the focus groups. "It's like when you're crossing the border to a different country. Here I feel you have absolutely no rights. You've been given up all your rights when you're committed or [inaudible] committed. And that is not correct. That to me goes against the Charter of Rights and Freedoms. [Others – "Yes!"] And that has to change." In discussions with a civil liberties lawyer during the course of the working group's collaboration with the BCCLA, the lawyer had remarked about the viability of a Charter challenge of the exclusion of psychiatric treatment from the Representation Agreement Act. If psychiatric patients are indeed not protected by the Charter, not protected against invasions of the security of their person or curbs upon their liberty or discrimination based on their disability then their predicament is truly a state of exception

under the rule of law. The denial of a competent decision-maker for a psychiatric patient is at the very least a kind of violation of an individual's self-determination.

“When I left I had sympathy with convicts. I absolutely had a sense of what they went through and how they felt.”

One participant had spoken to several participants of a program she administered and recounted the contrast between jail and psychiatric hospital. “Several of our members had been forensic psychiatric patients and had been in jail and all of them said that they'd way rather go to jail or prison than to a psychiatric hospital because there's an end to your sentence. It can't just be prolonged indefinitely and because you're less likely to be debilitated by drugs although you are somewhat likely to.”

## **Representatives**

Most of the participants in the focus groups supported the idea of having a representative as could be appointed under the Representation Agreement Act of BC. As one participant said, “I think that having a representative would offer hope. I thought that was really important. I would have an ally. I would feel informed...that somebody had my best interests at heart.”

Another participant talked about being treated as a competent adult. “So, the idea of allowing somebody to take responsibility and have some say is a fundamental aspect of adulthood in our society.”

Similarly, one participant spoke of humane treatment and human decency. “And, I think, having representatives would be one step towards having people who are hospitalized being recognized as human beings who should be treated with some decency.”

Other participants had criteria for what their representative should know or do. “You need somebody who's not afraid to speak out against the establishment.” Yet another was concerned with alternatives to treatment. “I think that having a representative that understood about alternatives is the way to go...” Another wanted some expertise on the part of the representative. “I want somebody who's relatively familiar with the medical field, even if it isn't directly related to mental health, because I think they would have a much better idea of the channels to move through.” Likewise another participant said, “Yeah, I think somebody who's worked as an advocate with legal understanding would be a good kind of person to have in this position.” Or this participant: “I think that a mental health lawyer or a good, compliant doctor like my own would be a good person.”

Expertise was a continual theme among the participants. “Some community advocates that I know in the community would be just terrific.” Or, “If I had the ability to appoint a doctor or a mental health lawyer who was on side and understood the issues and my needs that would be a good person.” Mental health consumers were also identified as good representatives. “So, I would choose somebody who's already identified as a consumer who are most people I know.”

Finally, participants were concerned with instructions they would want to give to their representative. “Well, as part of having a representative I would impart to this person and I would want it to be required of the hospital or medical team to direct any treatment that they were going to do, anything that was happening to me in the hospital,

that representative would be there, they would not proceed with changes, both physical or medical without my representative being part...being there to speak for me.”

## **Discussion**

From the discussion of the thirteen participants in the focus groups the lived experience of being a mental patient shines through in a way that is almost wholly absent from government sanctioned or government agency produced literature on mental health and mental illness. Would representatives be helpful to individuals committed to hospital? They would in fact be a wholly necessary, urgently necessary, support to the rights of committed mental patients, were we to judge the question from what these focus groups have brought up. However, this report cannot pretend to offer a reliable survey of opinions.

This exercise in PAR was not intended to provide exhaustive data or statistically significant quantitative data of any kind. It is not so much the drawing of scientific conclusions from this research that was intended as it is the attempt to bring into relief how psychiatric power is exercised over marginalized individuals and the effect it has had on them. But the perspective arising from this effort, if it is clear at all, may have the power to provoke practitioners in the field of mental health and members of the public into reviewing their assumptions about how mental health care is carried on in British Columbia. More than that this wholly volunteer effort at PAR has aspired to moving people to action.

What the data above describe are alienating experiences of powerlessness compounded by physical and emotional suffering. The result is not only the loss of trust in the system, but the loss of trust in family. Another consequence for the individual psychiatric patient is the loss of a feeling of citizenship, of the taken-for-granted belief that one has rights.

The decision to medically treat someone without her consent has profoundly moral and ethical dimensions. In that sense, it is also a profoundly human decision. Again the question arises whether someone who is paid to make such decisions is the best person to do this. The application of the right of representatives or substitute decision-makers to involuntary committals might more adequately address this moral and ethical kind of decision-making than would concentrating this power into the hands of a paid professional who is in some respects a medical bureaucrat, a physician and a judge. Focus group participant responses express a desire for the return of this kind of responsibility to the people who have a personal stake in treatment decisions and who have the confidence of the psychiatric patient being detained in a hospital.

## **What Next?**

It is clear from the legislation in BC around mental health care and from the statements of focus group participants that psychiatric patients have been treated as a class apart from the rest of society. And so stigmatized, they have not infrequently been the subject of coercive forms of treatment.

Certainly mental illness is a challenge that many individuals and our society as a whole have great difficulty dealing with. The question remains whether the current configuration of legislation and practice in BC is well suited to treating such individuals and is serving the community well.

Focus group participants felt discrimination inherent in legislation and practice in British Columbia is not serving psychiatric patients well. In fact, it is not serving the community well insofar as our society wishes to be humane, respectful of human rights and enlightened. Therefore, the current public model of treatment decision-making for involuntary psychiatric patients appears to be both inefficacious and ethically suspect in the context of human rights. A private model of treatment decision-making embodied by substitute decision-makers including legal representatives as provided for under the Representation Agreement Act of BC appears to be a way to overcome some of these deficits in the way psychiatric patients are treated in BC.

Whether legislators can be prevailed upon to review and change current practices or whether it will take a legal challenge to force the courts to decide upon change is not clear. What is clear is that the efforts of concerned citizens including patients themselves, medical practitioners, nurses, social workers and individuals from all walks of life are needed to effect change.

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*[The West Coast Mental Health Network had its core funding cut by the Vancouver Coastal Health Authority in 2013. Since that time, the Network has struggled to carry on its mission to provide peer-run peer support to individuals diagnosed with a mental illness. At the time of this writing the Network is at risk of losing its office space in the Downtown Eastside of Vancouver.]*

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