Mental Health and Patients’ Rights in Ontario: Yesterday, Today and Tomorrow
Mental Health and Patients’ Rights in Ontario:
Yesterday, Today and Tomorrow

20th Anniversary Special Report
May 2003
Disclaimer

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DEDICATION

Dedicated to the strength and humanity of every individual who has faced challenges and obstacles on their journey to wellness and recovery.
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ACKNOWLEDGEMENT

The 20th Anniversary of the Psychiatric Patient Advocate Office is a time for celebration and reflection. Our hope in producing this publication is that the articles we have assembled will stimulate both. Each author was selected because of the significant contribution they have personally made to our understanding of mental health. Their wisdom, dedication and commitment to their work are reflected in the articles they have contributed to this publication.

As we reflect on our own experience over the past 20 years, our thoughts turn to the many clients that have crossed our doorstep seeking assistance to give voice to their issues or support them in their self-advocacy. Their courage and resilience in the face of often extreme adversity has and continues to be an inspiration to the work we do.
We rarely appreciate mental health until we lose it. Those with first-hand experience of the effects of mental illness are the best ambassadors in the mission to promote public awareness. In this comprehensive report, patients, advocates, and professionals present concerns that arise directly from their encounters with mental health care. Many points of view are expressed, and together they reveal struggle and achievement, frustration and hope.

I am pleased to lend my support to this initiative, which brings together current reports from the front lines of mental health care. These eye-witness accounts show us the human cost of mental illness. They challenge our preconceptions by recounting stories of pain and the courage that overcomes it, loss and the will to live, barriers and the vision that transcends them.

Until my own descent into depression following a violent attack in South Africa in 1998, I had little real understanding of the devastating effects of mental illness. Now, like these authors, I am committed to speaking out. The more open we are in sharing our stories, the sooner the walls of misunderstanding will come down.

The stigma that has been with us for centuries casts a long shadow. Many people find it frightening that any one of us could succumb to mental illness, regardless of age or background. In fact, one in five Canadians will become mentally ill at some point in their lives. This is not an isolated problem that can be swept to the margins of society: it can affect our family, friends, colleagues, neighbours – and ourselves.

Fortunately for all of us, much has changed for the better in the 20 years since the Psychiatric Patient Advocate Office began its important work: patient advocacy, professional training, advisory services, and public education have changed public attitudes and improved the delivery of mental health services. The articles in this 20th Anniversary Report show how far we have come, and how far we have yet to go.
MENTAL HEALTH AND PATIENTS’ RIGHTS IN ONTARIO:
YESTERDAY, TODAY AND TOMORROW

AN INTRODUCTION

Vahe Kehyayan *

On the occasion of the 20th Anniversary of the introduction of the Psychiatric Patient Advocate Office (PPAO) it is natural to reflect on where we have been and where we are. It is also a time to look forward to determine how the PPAO and its advocacy and rights protection services fit in a changing mental health system. This 20th Anniversary Report, appropriately entitled “Mental Health and Patients’ Rights: Yesterday, Today and Tomorrow”, is a collection of articles and stories from those who have had a role in shaping mental health policy, legislation and services. The articles from service providers talk about the struggle to make a more responsive mental health system. The stories from individuals and families of persons with mental illness who have had direct experience with the mental health system have an important message to send to those responsible for the mental health system. Both are a reminder of how far we have come and how far we still have to go in promoting and advancing patients’ rights in Ontario.

Twenty years ago, the Ontario government introduced the PPAO as a provincial program to safeguard the rights and privileges of patients in the provincial psychiatric hospitals (PPH). There was recognition at that time that patients with serious mental illness were among the most vulnerable due to the nature of their illness, and the manner in which mental health services were structured and provided. It was also created as a response to the coercive and controversial nature of some treatments. Government recognized at the time that patients needed to have a voice in the services they were being provided. Today, the PPAO operates as an arm’s length program of the Ministry of Health and Long-Term Care under a Memorandum of Understanding (MOU). The Memorandum serves as a framework setting out our mandate and policy and administrative accountabilities to the Ministry and the Ministry of Health and Long-Term Care and assuring its independence from any political or bureaucratic interference in carrying out its mandate. Our clients have told us that our advocacy “independence” is one of its greatest strengths.

During the past 20 years, we advocated for or assisted many patients to self-advocate for their rights and privileges. Despite safeguards enshrined in the Mental Health Act, each year we addressed about 4,500 issues where patients’ entitlements, rights or privileges were compromised or threatened. We provided services from a “patient-first” perspective, developing over time a “client-centred” model of practice. The PPAO’s logo -- our corporate visual identity -- illustrates our independence from both the Ministry and service providers, and is a reflection of our relationship with our clients and our philosophy and approach. The PPAO’s logo is also significant to the work that we do with and on behalf of our clients. The heart shaped logo, with three divisions, places the patient at the centre with the advocate and the patient’s support network on either side. The logo represents the heart only when all three pieces are together. The PPAO believes that creating caring systems requires the effort of all those involved and places the patient at the centre. It is this commitment and passion for making life better for our clients that continues to motivate us in our daily work with patients, families and other stakeholders.

The PPAO is very proud of its accomplishments in its 20-year history. The PPAO owes these accomplishments to its dedicated staff, its clients, psychiatric facility staff and other stakeholders. One of the major initial tasks given to the PPAO upon its inception was to assess whether or not sections 66 and 67 of the 1978 Mental Health Act should be proclaimed. Based on information gathered and analyzed about rights violations, the PPAO recommended to the Minister of Health that these Sections should be proclaimed as a further step in the evolutionary process towards eventual compliance with the Charter of Rights and Freedoms. On March 1, 1984, the Minister implemented the PPAO’s recommendation and these sections were proclaimed in law. Over the years, the PPAO continued advancing patients’ rights despite challenges and resistance at times. To enhance the education of consumers and the general public about patients’ rights and entitlements, the PPAO published a series of Info-Guides and Rights Guides. To broaden public access to such educational material, the PPAO introduced a website that now receives more than 12,000 hits a month. The PPAO also had significant involvement in a number of law reform initiatives including submissions to the Weisstub Report (1990) on treatment incapacity, health information privacy legislation, and Bill 68, which expanded the civil commitment criteria and introduced community treatment orders, which require that patients in the community comply with a treatment plan. The PPAO diligently worked towards creating a balance in the amended Mental Health Act (December 2000) by making a requirement under the Act that patients, who are going to be placed on a community treatment order (CTO) received rights advice. This requirement also applied to patients’ substitute decision-makers, if any, if the patient was deemed incapable to make treatment decisions related to the CTO. We also played a central role in the development and implementation of a provincial rights advice program in Schedule 1 facilities.

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During the Ministry's negotiations with the Receiving Hospitals for the transfer of the governance of the provincial psychiatric hospitals, the PPAO was successful, in collaboration with the Ministry, in negotiating with the Receiving Hospitals to maintain the PPAO's services so that patients continued to enjoy the benefits of accessing professionally trained and competent and independent Patient Advocates to advocate on issues of concern to them. Since 1998, when the first provincial psychiatric hospital was divested (the Queen Street Mental Health Centre), the PPAO continues to operate in the six divested hospitals.

While our mandate was limited to the patients in the provincial psychiatric hospital, we shared our expertise with other countries and provinces and assisted them in their efforts to set up rights protection mechanisms for persons with mental illness. Furthermore, in recognition of increasing shift of patients' care and treatment into the community, and in collaboration with other stakeholders, the PPAO undertook a pilot project in Eastern Ontario to establish whether there was a need for advocacy services in the community for Assertive Community Treatment Team (ACTT) clients. The project confirmed that patients' vulnerability in the community, outside the walls of a hospital, only increased due to the multiple environmental and societal barriers to their successful reintegration into the community. Issues related to housing, landlords, finances, and access to appropriate treatment had to be dealt with and required a partisan Patient Advocate to help patients, now in the community, navigate through the system.

Perhaps our greatest accomplishment has been the ongoing work we have done to improve the quality of life and care for our clients on a daily basis. This work has involved individual instructed advocacy with clients and systemic advocacy efforts for the benefit of larger number of patients. This involved countless submissions and position papers on issues affecting clients' rights and entitlements; media involvement to raise public awareness of issues affecting patients' rights; and the introduction of voting rights for individuals with mental illness. While these are significant accomplishments, much work still needs to be done.

Mental health reform in Ontario is well underway and with this unprecedented change comes a period of uncertainty for our clients, their families, front line facility staff and the PPAO. We acknowledge that the past several years have been difficult for some; however, we recognize that with change comes an excellent opportunity to re-design the mental health system, to challenge the old ways of doing things and to create a system that better meets the needs of those that it is intended to serve. We are now providing service in a new environment and in a climate of change and renewal. The challenge for the PPAO is to make the reform of the mental health system a meaningful experience for our clients and to ensure that their voices do not get lost in the reform process.

During the deliberations of the Mental Health Implementation Task Forces regarding mental health system redesign, the PPAO shared its articulated vision for advocacy services in a reformed mental health system, outlining benefits for consumers, services providers and policy makers. The PPAO also had the opportunity to have discussions with some of the Task Forces about its articulated vision. We were very pleased to find that the Task Forces have all included some form of advocacy services in their recommendations to the Ministry of Health and Long-Term Care. Most of these Task Forces based their mental health system design on the concept of recovery. Over the past decade, this concept has been reshaping the manner in which mental health systems are being re-designed in North America and across the continent. The literature identifies advocacy and rights protection as one of many essential services in a recovery-oriented mental health system\(^4\). Recovery has been viewed as taking place at a number of different levels: the individual who is recovering from mental illness; the service organization that is supporting individuals in their recoveries; and the system level – the policies that have to be in place to support a recovery-oriented system\(^5\). An effective recovery-oriented mental health system must be geared to address each of these levels ranging from service delivery to help individuals with their mental illness to addressing systemic issues such as developing social policies that support their recovery, including accessible appropriate housing, employment and supportive services. It also involves addressing societal issues such as stigma, discrimination, and acceptance.

The Ministry of Health and Long-Term Care has long recognized that determinants of health lie beyond the immediate health care sector. They encompass factors such as housing, education, employment, and financial security. They also encompass less tangible factors such as independence, empowerment, self-esteem, the ability to make choices about housing, living arrangements, treatment modalities, or other aspects of clients' lives. The work of the Systems-Linked Research Unit on Health and Social Service Utilization at McMaster University supports this concept. Their key findings are that "vulnerability in an individual implies 'inequality' in the person's biological characteristics (age, gender, genetic endowment), personal resources (cognitive, emotional, intellectual), and/or environmental supports (social, material, cultural). While biological characteristics cannot be modified, personal resources and environmental supports can, and they could have a considerable economic effect.\(^6\) Thus, variation in an individual's personal resources or environmental supports can greatly alter the degree of their vulnerability or resilience, which in turn influences their use of health care services\(^6\).

It was shown in a research study in the United States that advocacy activities, which empower patients to voice their views about their care and treatment and to make
informed choices about them, have a positive impact on the patients’ quality of care and quality of life while either in the community or in a psychiatric facility. In this study, individuals with mental illness who were living in the community and who received advocacy services experienced significantly fewer days of subsequent hospitalization than a control group who did not receive such services. The difference in the hospitalization rates of the two groups disappeared after advocacy services were terminated. Thus, advocacy services can have a positive impact on patients’ quality of life and an economic impact on the mental health system resources.

Given the well-documented literature on the vulnerabilities of persons with mental illness, a well-positioned advocacy and rights protection mechanism could effectively intervene with and on behalf of these individuals, support their self-advocacy efforts, and therefore contribute to their recovery. We believe that a mechanism of advocacy and rights protection, one that is properly designed, implemented and coordinated, could play an essential role in Ontario’s comprehensive mental health system.

Accountability in the public sector is becoming increasingly complex as a result of developments both within and outside the government. As a result, the Ministry is introducing a new accountability framework for mental health services. A critical element in any effective accountability framework, aside from setting service delivery expectations and monitoring by government, is facilitating input and feedback from consumers and their families about the accessibility, availability and quality of mental health services. Such input and feedback would require a single point of contact for the Ministry to take the pulse of the consumer/survivor community regarding mental health services. A provincially established advocacy and rights protection mechanism can serve such a critical function – one that will ensure a balance in the Ministry’s accountability measures. Advocacy and rights protection services are not only essential for a comprehensive mental health services delivery, but will serve as an integral component of a balanced system of accountability. As the Ontario government develops accountability measures, it is necessary to include consumer perspectives.

Currently, formal and informal advocacy services do exist in Ontario; there are a variety of programs and services that provide advocacy at both the local and provincial levels. However, there is consensus that these services are fragmented, that there is a lack of provincial co-ordination and integration, and that there is a lack of a provincial framework with a corresponding accountability framework. In designing an advocacy model for the future, the PPAO and its stakeholders believe that advocacy services must be formally established, be independent from service providers and provincially coordinated, with both a local and regional presence so that the services are accessible to those who will utilize them.

As the Task Forces have acknowledged, advocacy should be an essential and integral component of a reformed mental health system and that advocacy should be available to all individuals with mental illness regardless of where and from whom they are receiving mental health services. That is, advocacy services must be attached to the individual instead of to a facility or service provider so that in a seamless service delivery system the individual would always have access to an advocate.

Advocacy services in a reformed mental health system under an umbrella organization would include such components as: training and certification of advocates; setting of standards of practice and conduct for advocates; developing public education material and conducting education to the general public and professionals about mental health legislation and patients’ rights; providing individual advocacy services; conducting regional or provincial systemic advocacy; training rights advisers; and providing rights advice in psychiatric facilities and in the community. Advocacy services in a reformed mental health system would be characterized by being driven from the client’s perspective; formal and informal advocates would provide services through partnerships; and clients would have a choice in who provides them with advocacy services. Services would be delivered through partnerships with stakeholders, consumer-survivor organizations, families and caregivers. The benefits of such a service delivery model would allow for the pooling of local and provincial talents and resources, collaboration on advocacy issues with a goal of the improvement of the mental health system. The envisioned advocacy services would complement and supplement other existing mechanisms, and not duplicate them.

The PPAO views mental health reform as a great opportunity for further advancement of patients’ rights, the inclusion of the patient as an equal partner in the treatment process and the involvement of patients in all decisions that affect their care, life and treatment. As a progressive society we must find new and creative ways to provide mental health care and treatment in an environment that is supportive, understanding and accepting of mental illness and that affords dignity and respect to all, regardless of their illness. We must begin to talk about “wellness and recovery” and to support individuals in their full participation in society.

A provincial patients’ rights protection mechanism would offer many benefits to consumers, service providers, and to policy makers. For the individual, advocacy would contribute to persons’ recovery process. It would afford them quality of life and care. It would also increase their successful integration into the community. For service providers, advocacy would serve as a catalyst to promote a culture of recovery, and be a catalyst to bring about change and greater understanding of patient rights issues. Advocacy, through early issue identification and intervention, serve as risk avoidance for health care
professionals and facility administrators. For the Ministry of Health and Long-Term Care, as social policy maker and primary funding source for the mental health system, a provincial mechanism would serve as a key leverage point for creating a culture of recovery in Ontario; would serve to break out silos such that there is equitable service to all; would serve as a single source of contact for taking the pulse of the community in terms of services provided and outcomes sought by consumers; and would serve as vehicle for the Ministry to achieve a balanced system of accountability. And finally, an advocacy and rights protection mechanism could serve as a quality check for the Ministry. By having an appropriate mechanism in place, the Ministry would have the opportunity to hear of alleged incidents, breaches of rights and entitlements provided in Ministry policy or legislation, and other potential deviations from desired standards of care and services. Such a mechanism would act as the proverbial “canary in a mine” for the Ministry, and through its systemic checks and balances, would provide tools for the Ministry to assess the availability, accessibility and quality of mental health services.

As we embrace the future, we need to make advocacy and rights protection services an integral component of mental health services in Ontario. While in the past 20 years we have made significant advancements in patients’ rights, we need to continue to offer advocacy services to vulnerable persons with mental illness to help them navigate the system on their road to recovery. We need to continue our collective efforts in advancing patients’ rights beyond where they are today. It would take collaboration of all stakeholders to create a system that has a client-centred philosophy, to make the mental health system more accountable to the people it serves, to create a community that is accepting, inclusive and understanding of mental illness and to give persons with mental illness a greater but equal voice in all aspects of mental health service delivery. You will find these messages of hope, inspiration, empowerment and forward thinking through this publication.

2 R.S.O. 1978, c. 50.
5 Nora Jacobson, Interview comments in Defining Recovery, Network, Canadian Mental Health Association, Ontario Division Winter 2003, pp. 6-9.
7 Rogers, A.C. Vulnerability, Health and Health Care. Journal of Advanced Nursing. 26(1), 65-72

* Vahe Kehyayan has been the Director of the Psychiatric Patient Advocate Office since August 1996.
Respect, compassion, dignity, human rights, and community service were values that were instilled in Larry Grossman by his family from the start. Larry would recall how, as a young boy waking up each morning, he would hop out of bed and tiptoe around refugees who had been taken in for the night by his parents in the aftermath of 1956 Hungarian Revolution. He understood what was expected of him: he was to “add value” to the world by being in service to the communities of which he was a part.

When he arrived as Minister of Health in 1981, Grossman was clearly a star cabinet minister in the government of Bill Davis. As Minister of Industry, he had been innovative and bold in his efforts to support the transformation of Ontario’s economy from its traditional industrial base to the underpinnings of what has now evolved into the knowledge economy.

As a cabinet minister, Grossman was visionary, highly strategic, and courageous. He was determined to make a difference in the world that he inherited.

By his third day as Minister of Health, Grossman had exchanged his pinstriped suits for blue jeans and a T-shirt as he toured Parkdale with ex-psychiatric patient activist, Pat Capponi – who today is a successful Canadian writer.

Pat Capponi did not give Mr. Grossman a nice safe ministerial tour. In the late 1970s, the provincial government had closed thousands of institutional psychiatric beds – in part due to budget constraints, in part due to changing treatment patterns – but they had no, or very few, support programs in the community.

Releasing thousands of patients with only a packet of pills and a pat on the bum had produced a major crisis in downtown Toronto. Deplorable living conditions and what coroner juries called “death by therapeutic misadventure” were the results of government policies that had no vision and no strategy for the traditional “poor cousin” of Ontario’s health care system: the mental health care sector.

Shaken by Pat Capponi’s real-world tour of Parkdale’s Kafkaesque boarding houses, and by his conversations with the ex-psychiatric patients he met, Grossman vowed he would transform the provincial mental health system – and in particular, provide dignity, respect, and meaningful support for those who needed it, where they needed it.

As he dug deeper and learned more about mental health issues over his first several months at the Ministry of Health, Grossman began to develop a much more comprehensive approach that was based on the advice of the mental health reform advocates that he surrounded himself with.

Steve Lurie, Aileen Meagher, Brian Davidson, Mary Ellen Polack, Ron Ballantyne, Tyrone Turner, and numerous front-line support workers collaborated with Grossman and his staff to craft policies and programs that would enable the system to evolve to meet the changing needs of the people it was intended to serve.

Within 18 months of his arrival at the Ministry of Health, Grossman had a new Mental Health Act focused on patients’ rights, a Psychiatric Patient Advocate Office, and an expansion of community-based mental health and support programs that sky-rocketed from $12 million per year to $54 million.

But what Grossman understood was that money and laws alone would not fix the system: what was needed was a fundamental shift in the way we think about mental health – within the mental health system itself, and within the public.

For the public, Grossman, through his partnership with the provincial arm of the Canadian Mental Health Association, sponsored large-scale award-winning radio and television commercials that appealed for public support for the reintegration into the community of fellow citizens who had experienced a mental health problem.

Grossman understood that the real struggle for shifting attitudes would be in the mental health care system itself – among administrators and mental health professionals. That is why he placed special emphasis on the role of the Psychiatric Patient Advocate Office (PPAO) as the key leverage point in the system. Grossman wanted the PPAO to have a profound impact on the culture that had evolved within the system.

“Our challenge,” said Grossman, “is to change the very culture of the system. We need to help administrators, professional practitioners, and Ministry of Health officials to change the way in which they think about mental health and patients’ rights.”

The Minister’s strategy for shifting an ingrained way of thinking about mental health included:

- creating a new Division for mental health within the Ministry, and appointing Dr. Boyd Suttie as the Assistant Deputy Minister for the new mental health division – at the same management table as the ADMs for hospitals and OHIP payments;
- recruiting a new breed of chief administrators for most of the 10 provincial psychiatric hospitals within a year; and
• recruiting Dr. Tyrone Turner to be the first Director of the Office of the Patient Advocate.

While Grossman had the full support of his cabinet colleagues for his mental health reforms, the appointment of Ty Turner – a former NDP candidate – did provoke some negative feedback from the Tory cabinet minister who had beaten Dr. Turner in the previous election.

But Grossman held firm. He believed that it was essential to ensure the independence of the office – which he believed the Tyrone Turner appointment achieved.

From his new stature as a senior Director in the Ministry of Health bureaucracy, Dr. Turner was able to work with the full cooperation of Deputy Minister Graham Scott, ADM Boyd Suttie and fellow Director, David Corder, as he set up the initial systems, structures, and processes that would achieve a fundamental shift in the way the system and the people in it understood “patients’ rights.”

So, here we are – 20 years later. Did the Psychiatric Patient Advocate Office achieve its intended purpose? Did Larry Grossman’s mental health reform strategy work?

As someone who worked with Mr. Grossman on his various strategic initiatives, I feel close enough to his thinking to say that if Larry were alive today, he would be very proud of the people from Tyrone Turner to Mary Beth Valentine to Vahe Kehyayan -- and all the people who worked for them – who made his vision come true.

I can also with some confidence predict that if Mr. Grossman were with us today, immediately after applauding and celebrating everyone who had contributed to the success of the PPAO, he would ask the following probing questions: “Are we as consumer/survivor-focused as we ought to be?" “Are we truly accountable for designing and delivering services that are grounded in the perspectives of consumer/survivors?” “If the program has proved itself in the former provincial psychiatric hospital system, why isn’t it available to the people who need these supports – wherever they are in the health care system?”

He would remind us of the core values that must drive our thinking and behaviour – the values of respect, compassion, dignity, community service, and human rights. Then he would explain to us how in fact … we could be doing much better!

We could have advocacy for individuals with mental illness who are using or trying to access mental health services anywhere in the system and who need the help of a professional advocate to help them navigate the system -- independent of system managers, service providers, and policy-makers. Such services could range from focusing on individual issues to addressing systemic ones -- including system design, monitoring and evaluation – all from a consumers’ perspective.

Knowing Larry, those would almost certainly be the types of probing questions, universal values and “pushing of the envelope” that my dear friend and former boss would talk to us about at PPAO’s 20th anniversary celebration. And these are the things that the mental health community, the Ministry of Health, and the PPAO must continue to ask themselves as they work to continuously improve the mental healthcare delivery system.

* Ted Ball was Larry Grossman’s Chief-of-Staff and Senior Policy Advisor at the Ministry of Industry, the Ministry of Health, and the Ministry of Finance. Today he is a partner in Quantum Learning Systems – an innovative firm that helps organizations to develop their own internal capacity to redesign themselves as customer-focused service providers.

THE EARLY ORIGIN OF THE PSYCHIATRIC PATIENT ADVOCATE OFFICE

Ty Turner

The Psychiatric Patient Advocate Office (PPAO) officially opened on March 1, 1983, after more than a year of planning within the Ministry of Health. It was a dynamic time when many different forces were converging.

During the 1970s and early 1980s, the struggle for patients’ rights was becoming heated. Groups of ex-patients, lawyers, civil rights advocates, and mental health professionals were pushing for change. At the time, there was a great deal of optimism about the new Charter of Rights and Freedom as a way of redressing long-standing injustice and discrimination. After receiving Royal Assent on April 17, 1982, the Canadian Charter of Rights and Freedoms’ equality provision, Section 15, was scheduled for delayed implementation, three years later in 1985.

Intended to forbid discrimination based on various demographic identifiers, including physical and mental disability, s.15 was expected to bring mental health laws up to date to provide a much higher standard of natural justice (due process). The consequent “Charter
challenges” were sometimes visualized as a deluge of litigation which would transform the landscape.

Additionally, there had been a great deal of negative publicity cast on the provincial psychiatric hospitals since the 1960s, when Metro Toronto’s coroner, and later MPP, Dr. Morty Shulman, conducted unannounced visits to mental hospitals and publicized the lack of resources and poor patient care. More recently, in 1981, three tragic deaths which occurred at Queen Street Mental Health Centre had become the focus of a coroner’s inquest, which was well covered in the media. Perhaps the Provincial Psychiatric Hospitals did not stand a chance, since long before, the provincial government, along with most other governments in the Western world, were cutting back state-run hospitals through a process of what we now call deinstitutionalization. A 1982 poll commissioned by the Ontario government showed that public confidence in psychiatric hospitals was far lower than for general hospitals, and other elements of the health care system.

Into all of this came a group of activists, many of them former psychiatric patients who, using street theatre and the Saul Alinsky methods, captured the attention of the media and the public. They were geniuses.

During this period, the American Psychiatric Association held their annual conference in Toronto, probably the largest gathering of psychiatrists in the world. Outside the venue, the activists acted out a mock portrayal of the forced injection of a psychiatric patient, by a brutal-looking staff member. The syringe, over six feet in length and a few feet wide, was poked into the backside of a “patient” who was being “restrained” on the pavement outside the building. This played well on the front pages of the newspapers. Later, in 1980, activists protested the building. This played well on the front pages of the newspapers. Later, in 1980, activists protested the

There were some individuals whose contribution to the start-up was crucial. The new Minister of Health, the late Honourable Larry Grossman, made mental health care a priority. He personally visited rooming houses and mental hospitals. The Deputy Minister, Graham Scott, was a keen legalist very concerned about legal standards for the protection of psychiatric patients’ rights. Ted Ball, Mr. Grossman’s senior policy advisor, helped bring all the parties together. Dr. Boyd Suttie (then Associate Deputy Minister of Health) and David Corder (later Assistant Deputy Minister) were also key figures who stickhandled the notion of psychiatric patient advocacy through government.

Early on, the ostensible need for patient advocacy programs involved 1978 Mental Health Act upgrades which provided for considerably more natural justice. Specifically, there were two sections (66 and 67) which were intended to deliver a more independent, potentially adversarial review of involuntary hospitalization. Highly controversial and resisted by the psychiatric profession at the time, these sections had not yet been proclaimed despite the passage of the main body of the amended 1978 Mental Health Act. With the unproclaimed sections hanging in the atmosphere like a lead balloon, and the charter equality sections about to become law in 1985, changes clearly had to be made.

From the beginning, it was expected that a patient advocacy scheme would “open up” the mental health system, and not simply prepare it for the proclamation of the natural justice sections. Parallel to this, other reforms were being implemented. These included establishing advisory boards and later patient councils for each hospital, and perhaps most significantly, improved management systems and more clinical resources in psychiatric hospitals.

Once the government determined the direction and developed basic terms of reference, the program development raced along, but quickly hit a snag. Presumably, because of the program’s need to advocate for persons who were provided care from within the same ministry, there was a great deal of attention paid towards perceived conflict of interest. This generated criticism from some quarters. To address this problem, the program was established to be quasi independent of the Ministry. To some extent the name, Psychiatric Patient Advocate Office, reflects this. More fundamentally, the advocates reported up to the higher reaches of the Deputy Minister and Assistant Deputy Ministers and not to hospital administrators.

From the outset, many points of view were canvassed, both inside and outside the provincial government system. Various voluntary organizations, such as the Canadian Mental Health Association, were highly supportive, as were clusters of civil rights lawyers and mental health advocates. The Law Society of Upper Canada was an early supporter. There was also considerable unofficial support from physicians, nurses, and social workers, and other care provider groupings. Meanwhile, the public service union was wary.

In the beginning, all ten psychiatric hospitals were visited by program development staff, including myself, an administrator, Susan Atkinson, and our lawyer David Solberg. Some of the meetings with staff were supercharged and even angry. Some professionals were offended by the notion that advocates were needed to protect patients from their ministrations. Until then, they had seen themselves as the principle patient advocates. Independent advocacy, that is, independent of the care team, was not always understood. Naturally, staff were anxious about “lawyers running around all over the place.” They were somewhat relieved when they learned that there was no intention for the patient advocate program.
to be highly legalistic. Since the program was designed to respond to patients' self-stated wishes (in contrast to needs, as determined by professionals), the program's advocacy needed to extend far beyond the narrow confines of legal rights. Reflecting this, the early program development team conceptualized two other forms of advocacy to be pursued by patient advocates. These are therapeutic advocacy and social advocacy. Therapeutic advocacy could mean improved communication with the doctor, perhaps to have information about medication, or to change programs. Social advocacy was about helping patients achieve their social service entitlements, including access to work and housing.

Reflecting the different kinds of advocacy, the first advocates were chosen from a wide variety of backgrounds. Besides lawyers, they included nurses, social workers, a minister, human rights specialist, and a former trade union advocate. All were mature, highly experienced and frequently called upon to provide “educational” within the hospital system, or outside, for volunteer organizations or the public at large. There were frequent requests for media interviews. For instance, a full op-ed article in the February 6, 1984, Globe and Mail, was headlined “The Struggle for Mental Patients' Rights,” and was about the advocacy program. There was also an article in Macleans magazine, and frequent appearances on television talk shows, radio and phone-in programs. In the media, patient advocates were often set up against mental health activists who complained that the advocacy program did not go far enough.

During the early years, there were frustrations, but overall there was a feeling of high energy and achievement, in the sense that we and our supporters were involved in a process of changing consciousness about the rights and entitlements of psychiatric patients. The work of therapeutic advocacy was slow to catch on, but there were significant gains. In some areas, this was facilitated by the Minister's appointment of patient advocates, under section 5 of the Mental Health Act, which assigned full inspector power to examine all documents and visit all hospital areas without notice. Daily incident reports were analyzed for clues about such things as worrying patterns in the use of restraints. Once identified, the patients’ advocate often worked closely with health professionals to establish policies to improve clinical care and reduce the need for restraint. Access to fresh air and exercise was an early focus. Additionally, the advocates became involved in allegations of abuse. On a more systemic level, the Psychiatric Patient Advocate Office was able to advocate for the inclusion of sheltered workshops in labor standards and occupational health and safety regulation. Through discussions with the Ontario Housing Corporation, as it was then known, PPAO contributed to a change in housing policy which eliminated discrimination against psychiatric patients in subsidized housing. A great deal of work was undertaken to help psychiatric patients secure the vote in the 1985 provincial election. We were involved in organizing all candidates' meetings, polling and vote counting. Later, the PPAO examined the voting results in provincial psychiatric hospital polls and found that psychiatric patients voted along almost the same lines as the general population.

Meanwhile, there was the steady push to proclaim the natural justice sections of the 1978 Mental Health Act. The PPAO participated in the development of the rights advisor scheme, which supported those sections, and eventually they were proclaimed in 1984. In 1986, the PPAO contributed to the passage of more amendments to the Mental Health Act, further contributing to a focus on the rights of psychiatric patients.

There were successes, failures, and disappointments. From the beginning it was understood that eventually the PPAO would extend to general hospitals and the community, at the same time becoming more independent. This has not happened to the degree originally anticipated. We saw significant improvements in the care of patients in psychiatric hospitals and could see this continuing, reflecting the hard work of staff and administrators. But in spite of this, the emerging government policy became highly focused on divestment of the provincial psychiatric hospitals to public boards.

Over the past 20 years, the mental health system has changed a great deal. There have been further bed closures and greater emphasis on community-based care. As well, the notion that patients have equal rights and protections is now rarely ever challenged within the mental health system. Surely, the Psychiatric Patient Advocate Office and all its friends and supporters have contributed to this.

RIGHTS ADVICE

Linda Carey*

Rights advice is a process by which patients in psychiatric facilities and persons in the community who are being considered for community treatment orders (CTOs) are informed of their rights when their legal status has changed. In the case of community treatment orders, if the person is incapable of making a decision regarding the proposed treatment (the community treatment plan), the person’s substitute decision-maker (SDM) must receive rights advice. Rights advice is an important component in the system of checks and balances established under the Mental Health Act and its regulations for the protection of the rights of the individual.

Rights advice is currently mandatory in nine situations, which are set out in the MHA and its regulations. These are:

- a physician’s decision to admit an individual as an involuntary patient, or to change the patient’s status to involuntary;
- a physician’s decision to continue the patient’s involuntary status;
- a physician’s decision that the patient is incapable to manage his/her property;
- a physician’s decision that the patient’s incapacity to manage his/her property must continue;
- a physician’s decision that the patient is incapable to consent to treatment for a mental disorder in circumstances set out in the regulations to the MHA;
- a physician’s decision that the patient is incompetent to consent to disclosure of his/her clinical record;
- a physician’s decision that the patient is incompetent to examine his/her clinical record;
- when a 12-15 year old is admitted to a psychiatric facility as an informal patient;
- before issuing or renewing a CTO, a physician must be satisfied that the person who will be subject to the CTO and his/her SDM, if any, have consulted with a rights adviser and been advised of their legal rights.

Rights advice was not always a part of the checks and balances contained in the MHA. Rights advice was embodied in the MHA as a result of the Canadian Charter of Rights and Freedoms, most of the provisions coming into force on April 17, 1982. Among other things, it guaranteed every Canadian the right, on being detained, to be told the reason for the detention, and to be told of his or her right to retain and instruct legal counsel without delay. Section 15 of the Charter, the equality rights section, was delayed three years in order to give the federal and provincial governments time to review all legislation and amend it to comply with the Charter. The review of Ontario’s legislation resulted in a number of changes being made to the MHA to ensure adequate due process protection to inpatients of psychiatric facilities whose rights were in some way suspended under the MHA.

In 1984, some previously unproclaimed sections of the MHA were proclaimed into force. Among other things, the sections obliged psychiatric facilities to notify the Legal Aid Area Director whenever a patient was detained in hospital on a Certificate of Involuntary Admission (Form 3) or Certificate of Renewal (Form 4). The notification did not trigger any action by the Area Director. The sections also gave the patient the right to apply to what is now the Consent and Capacity Board for a review of a physician’s decision that the patient was not mentally competent to make decisions about treatment.

In 1986, rights advice became mandatory for patients who were detained as involuntary patients. The question then became who should provide the rights advice. The PPAO delivered rights advice in the ten current and former Provincial Psychiatric Hospitals (PPHs). The PPAO hired and trained individuals to fulfill the role of rights adviser in each of the ten facilities. In specialty hospitals and general hospitals with mental health units, the notifications already sent to Legal Aid now triggered action from the local Legal Aid office. Rights advice to these inpatients was delivered by duty counsel (lawyers paid by Legal Aid) assigned to visit involuntary patients.

Amendments to the MHA in 1987 expanded the number of situations in which the provision of rights advice was mandatory. Rights advice was now provided to patients who were found incompetent to make treatment decisions, incompetent to manage property, and incompetent regarding their clinical record. There were now eight mandatory rights advice situations.

On April 3, 1995, the government proclaimed the Consent to Treatment Act, the Substitute Decisions Act, and the Advocacy Act. These legislative changes had a significant impact on the provision of rights advice. Rights advice was no longer restricted to situations under the MHA and to inpatients in mental health facilities. In fact, the number of rights advice situations increased from 8 to 29. The situations were a combination of mandatory rights advice (i.e., involuntary patients) and rights advice at the request of the person impacted by the loss of decision-making authority (i.e., incapacity to make decisions about medical treatment). Rights advice was provided in psychiatric facilities and in the community in a variety of situations specified in the MHA, the CTA, and the SDA.

The legislation also changed who provided rights advice. The Ontario Advocacy Commission was created and one of its functions was to provide rights advice in the 29 situations. The Commission’s community rights advisers
provided rights advice to inpatients in specialty hospitals and on mental health units in general hospitals. In essence, the Commission took over the role Legal Aid had been fulfilling. The PPAO continued to provide rights advice in the ten current and former PPHs.

On March 29, 1996, the Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, 1996 came into force. Among other things, the provisions reduced the number of mandatory rights advice situations from 29 to 8. The 8 situations are mandatory pursuant to the provisions of the MHA and its regulations.

The legislation also disbanded the Advocacy Commission and a new scheme for rights advice was created. The PPAO continued to provide rights advice in the 10 current and former PPHs. Rights advice in specialty hospitals and mental health units in general hospitals was provided by one or more individuals designated by the facility to act as a rights adviser. The majority of facilities designated facility staff to provide rights advice services. Some facilities designated private contractors or volunteers to provide the service.

The PPAO, under the auspices of the Ministry of Health and Long-Term Care, provided training for those individuals who would be providing rights advice as designees of the specialty and general hospitals. The PPAO has continued to provide training for its own rights advisers and those designated by other facilities.

The 1996 amendments to the MHA defined who may be a rights adviser. The rights adviser is a person or a member of a group of persons appointed by the Minister of Health and Long-Term Care (the Minister) or designated by a psychiatric facility to provide rights advice. The rights adviser may not be a person involved in the direct clinical care of the person who will be seen by the rights adviser. Thus, a member of the treatment team may not be a rights adviser. The PPAO rights advisers are independent of the facilities in which they provide rights advice services. They are not members of the treatment team.

In 1996, the regulations to the MHA were amended to include the requirements a person designated by a psychiatric facility must meet to be a rights adviser. The rights adviser must:

- be knowledgeable about the rights to apply to the Consent and Capacity Board under the MHA and the Health Care Consent Act,\(^7\)
- be knowledgeable about the workings of the Board, how to contact the Board and make applications to the Board;
- be knowledgeable about how to obtain legal services; and
- have the necessary communication skills to perform the function of a rights adviser effectively.

Amendments to the MHA, which became effective on December 1, 2000, impacted on the provision of rights advice in several ways. A new rights advice situation was created. Before a physician may issue or renew a community treatment order, he/she must be satisfied that the person subject to the CTO and his/her substitute decision-maker, if any, have consulted a rights adviser and been informed of their legal rights. There are now nine mandatory rights advice situations under the MHA.

The provision of rights advice was extended into the community for persons who are not inpatients of psychiatric facilities and who are being considered for a CTO, and the substitute decision-maker, if any. The person subject to the proposed CTO may be either an inpatient in a psychiatric facility or living in the community (not an inpatient). The Minister has designated the PPAO to provide rights advice to persons who are being considered for CTOs when they are not inpatients of psychiatric facilities.

The amendments also expanded the 1996 definition of a rights adviser by adding to the group of persons who may not be a rights adviser. A person providing treatment or care and supervision under a CTO may not be a rights adviser.

The 1996 requirements to be met before a person may be designated to perform the function of a rights adviser were expanded in December, 2000. Regulation 741 to the MHA requires the person to have successfully completed a training course for rights advisers approved by the Minister and to have been certified as having completed such a course. The Minister has approved the PPAO's training course for rights advisers. The knowledge requirements now apply to all persons being designated to perform the function of a rights adviser.

In the fall of 2000, the PPAO trained all designated and proposed rights advisers in the province in the new provisions in the MHA. The PPAO trained over 280 people across the province.

The amendments to the regulations include a provision giving psychiatric facilities designating their own rights adviser the option of designating the PPAO to provide this function. The PPAO's Community-based Rights Advice Program began operation on June 18, 2001. The PPAO has trained and has contracts with over 40 rights advisers to provide rights advice services in over 40 facilities across the province. In 2001, the Community-based Rights Advice Program received requests for rights advice on 8774 forms.

The history of rights advice has seen changes in the number of rights advice situations and in who provides the rights advice to the individual. Throughout this time, several statements about rights advice have remained constant. The rights adviser must be independent and provide rights advice in an impartial and non-judgmental manner. The quality of rights advice should be consistent
throughout the province. The rights adviser must be knowledgeable about patient rights to apply to the Consent and Capacity Board, the workings of the Board, and how to obtain legal services.

Rights advice is essential to the preservation of due process for individuals whose rights are suspended under the MHA. The PPAO is committed to the provision of quality rights advice services. To ensure the quality of rights advice services, training and consultation must be available to the rights advisers.

The PPAO will continue to provide training for all rights advisers as well as consultation to rights advisers regarding rights advice situations.

* Linda Carey, Manager, Community-based Rights Advice Services, Psychiatric Patient Advocate Office (PPAO).

**MENTAL HEALTH RIGHTS ADVICE AND ADVOCACY: AN ADMINISTRATOR’S PERSPECTIVE**

Ron Ballantyne *

It is apparent from the history of mental health care in Ontario that mental health consumers, by virtue of the severity of their illnesses, are not always able to comprehend their circumstances at critical points in their life and, most important, act on their own behalf in achieving their best interests and choices. These critical points occur typically, but not exclusively, at a time leading up to and following an admission to a psychiatric facility. Whether making decisions about treatment, whether challenging an involuntary hospitalization, whether advocating legal entitlements or whether seeking information about community services, the myriad of challenges facing someone who is experiencing a severe mental illness are often insurmountable. The most pertinent question to ask at this important stage in the consumer’s life is whether guidance from the clinical team, rights advice and advocacy are always available when needed?

In the normal course of the provision of inpatient or outpatient treatment in a mental health facility, consumers expect to receive appropriate information about what type of treatment is available to them, why the treatment is indicated and what the consequences are of the treatment. Providing this information and delivering acceptable services is a basic duty of the health professional and the psychiatric facility responsible for the care of the consumer. However, some of the most critical decisions regarding treatment and care are made at a time when the consumer is overwhelmed with the symptoms of the mental illness, when there are rapidly changing social and familial circumstances and when exposure to new surroundings and unfamiliar people dominates the consumer’s life. For the facility administrator, the moral and ethical challenge arising from this time of vulnerability for the consumer is how to ensure that consumers’ clinical needs are met effectively in an environment of dignity, respect and understanding while giving deference to the individual and legal rights, quality of life and informed choice. Balancing these fundamental principles is not easily accomplished.

Since 1983, Provincial Psychiatric Hospitals (PPHs) in Ontario have had the advantage of the Psychiatric Patient Advocate Office (PPAO) being available at arm’s length to provide rights advice and instructed advocacy to inpatients under mental health legislation. From both the consumer’s and the mental health facility’s perspective this role has proven to be very valuable. For the consumer, whether newly admitted or having been in the hospital for a period of time, there is assurance that rights advice and advocacy is readily available as needs dictate. For the mental health facility administrator, there is satisfaction in knowing that all inpatients are receiving appropriate rights advice in accordance with the legislation and that there is the option for a consumer’s concern to be conveyed independently of the facility’s normal complaint resolution process if desired. Instructed advocacy by the PPAO over the past two decades has often led to significant changes in policy and practice, hence contributing to a higher standard of care. Another component of the PPAO mandate, systemic advocacy, has been more controversial.

With the year 2000 amendments to the Mental Health Act, the PPAO’s mandate was further expanded: to provide rights advice to all Schedule 1 mental health facilities, where designated; to provide rights advice to consumers in the community who are being considered for community treatment orders; and to provide training for rights advisers. This has resulted in rights advice being more widely and consistently available across the province.

In many ways, this expanded PPAO mandate has been a step in the right direction to achieving the goal of
providing rights advice and advocacy to all vulnerable mentally ill consumers whether living in the community or treated in a hospital. Mental health executives and professionals have often pointed out that a consumer living in the community, under certain circumstances, requires rights advice and instructed advocacy equal to that available to the inpatient in a mental health facility. In some situations it is difficult or inappropriate for the attending mental health professional to fulfill this role.

When it is recognized that the central aim of mental health reform policy in Ontario is to achieve both quantitative and qualitative community integration for mental health consumers, it is clear that a key component of this goal can be facilitated by ensuring that vulnerable consumers have reasonable access to rights advice and instructed advocacy. Of course, these services should not be considered a higher priority than a full range of mental health supports and services in a comprehensive community system (e.g., housing, peer support, income support, employment options, case management, crisis intervention, treatment, specialized supports, family supports, etc.). Rather, rights advice and instructed advocacy should be woven into the fabric of a comprehensive community system. In this way, for example, the consumer who is still in the early stages of his recovery from his illness and is incapable of dealing with an eviction or is struggling with community treatment options could access independent advice or advocacy especially oriented to consumers with mental health difficulties.

Every mental health facility administrator knows that consumers with serious mental illness can be best served with a full range of community supports and services complemented by access to specialized acute and specialized hospital based services. This includes rights advice and instructed advocacy at all key junctures in the mental health continuum. Our goal in Ontario is to achieve better consumer outcomes and to accomplish more effective community integration despite the formidable psychiatric and social obstacles faced by consumers. Assuming there is a firm commitment to overcoming these obstacles, it is realistic to expect major advances toward this goal in the near future.


REMEMBERING THE '80S: LESSONS AND NOSTALGIA

Peter Bartlett

There is a sense in which I see the mid-1980s as something of a golden age in mental health advocacy and mental health reform in Ontario. It was a time of optimism. The Abella Report1 in 1983 had given advocacy for people with disabilities a profile among policy makers. The new program of patient advocates in the ten provincial psychiatric hospitals was instituted the same year, with rights advice following throughout the psychiatric system two years later. The introduction of the Canadian Charter of Rights and Freedoms2 in 1982, with the equality provisions of section 15 coming into effect three years later, provided new avenues both politically and in litigation for mental health advocates. These were heady times.

Very good people were there to breathe life into these forms. The first round of appointments at the Psychiatric Patient Advocate Office (PPAO) were astonishingly strong. That applies not only to the advocates themselves, but also to their managers. No doubt Ty Turner will be justly praised elsewhere in this volume; for the purposes of this article the first Legal Director, David Solberg, is a particularly important figure. Solberg had the ideal combination of traits for his job: an unswerving and slightly idealistic devotion to the rights and dignity of people considered to be mentally disordered, a knowledge of how government bureaucracy worked, a legal mind like a steel trap, and a genuine warmth of character. He established an ethos around the PPAO’s legal thinking at the beginning; sadly, his death in 1986 meant that he did not live to see many of the successes of his early leadership. Elsewhere in the system, there were also remarkably strong advocates and reformers: David Draper at Parkdale Community Legal Services; Carla McKague, Michael Berman and Jane Arnup, then all in private practice; and Mary Marshall, then at the Canadian Mental Health Association (Ontario Division) are obvious examples, but there were many others. The user movement was broadly healthy, publishing a magazine, Phoenix Rising, more or less regularly and engaging in a variety of political activities. At the Ministry of Health, policy makers such as David Corder and Gilbert Sharpe as well as a range of staff lawyers provided a willingness to engage with the debate – a contribution we should not undervalue.

In this article, I want to recall some issues of law reform from the mid-1980s, and ask what lessons we may draw now from those years.

At the centre of the pressures for reform was a loose-knit organization called CLIP, the Committee for Legal Issues in Psychiatry. This group met monthly at Parkdale...
Community Legal Services in Toronto from the spring of 1985, and lasted until late 1988 or early 1989, by which time many of its core participants had moved on. Those attending included a roughly equal mix of lawyers in private practice and PPAO advocates, with a smattering of enthusiastic students such as myself. That combination of lawyers and PPAO advocates was pivotal to the group’s success: litigation strategies could be swapped between the members, ensuring that suitable test cases could be identified, and appropriate reforms instituted. And there was mutual support. There was no doubt in anyone’s mind at those meetings that those present were doing important and exciting work.

It was a watershed period for the substance of mental health law in Ontario, particularly in the area of psychiatric treatment. At the beginning of this period, absent appointment a guardian under the Mental Incapacity Act, a torturous process, voluntary patients over the age of 16 and lacking treatment capacity could not legally be treated. Treatment decisions for involuntary patients lacking capacity could be made by their next of kin, as defined by the statute, but no guidance was provided as to how those decisions were to be made. And either the refusal of the next of kin or the refusal of the competent involuntary patient himself or herself could be overridden by the review board, essentially on the grounds that the treatment would benefit the patient. There was no way short of judicial review to challenge a doctor’s view that the patient lacked capacity, and the anecdotal evidence was clear that capacity could often be equated with agreement with the doctor. Rights of access to clinical records and information were limited: the patient had a general right to see documents presented to the review board (frequently, only a summary of the file, prepared by the doctor), but otherwise, the medical professionals took the view that disclosure of the clinical record was entirely discretionary.

Review boards were also not generally held in high esteem at the beginning of the period. Too often, it seemed that the statutory criteria at issue were viewed at best as guidance rather than as legal standards, and the appointments process was perceived as motivated by political patronage rather than by any notable expertise in mental health law. There did not seem to be a sense that the boards in question understood their role as legal guardians of very important rights. The orders authorizing treatment, for example, would not necessarily be specific as to what treatment should be offered, or in what range of doses, and it was sometimes a battle to get the boards to seriously consider whether the relevant statutory criteria of admission had been met.

By the end of the decade, much of this had altered. A new foundation of mental health law had been laid, separating confinement from treatment decisions, and introducing capacity as the pivotal distinction in the latter context: now, all competent patients would have a right to refuse treatment, and all incompetent patients would be treated on the consent of a substitute decision maker. The emphasis on capacity moved into other areas of the Act as well: the competent patient could now appoint a substitute to make decisions in the event of incapacity, and wishes regarding treatment made while capable would bind the substitute in the making of decisions. It was, at least on paper, a new world.

The Review Board structure was also fundamentally altered. This was in part substantive: issues such as a doctor’s finding of incapacity could be challenged before the review boards for the first time. Procedural change was also significant, however. Hearings were now to be held within seven days, not 28. Reasons were routinely to be given. And, perhaps most significant of all, changes in personnel meant that the review boards began to take legal argument much more seriously.

I was astonished a couple of years ago to hear a prestigious Ontario psychiatrist tell an international conference that the move to provide competent involuntary patients the right to make treatment decisions had been the idea of the psychiatric profession. It was not – indeed, they fought against it tooth and nail – but the fact that at least some of them now claim it as their own goes a long way to showing how successful that reform has been. I am less convinced that decisions about capacity are being made in the way envisaged by the Act. I suspect it is still the case that patients who consent get given the prescribed drugs, even if they lack capacity. Even if the incompetent patient refuses, psychiatrists have told me off the record that an attempt is often made to “cut a deal” on less intrusive medication which the patient will accept, in order to avoid the hassle of getting consent from the substitute decision maker. This seems consistent with perception that few applications relating to capacity are made to the review boards. As one psychiatrist put it to me, “Where’s the harm in that?” Well, the harm is that the substitute decision-maker is supposed to provide a check on inappropriate medication. Our view when we lobbied for the changes was that drugs can hurt as well as help, and someone ought to provide a second view to that of the doctor. How well that system works in practice is a fair question.

The question of application is in part downward-looking, to the decisions the law does not normally see, as in the question of how substitutes are in fact making decisions. It is also upward-looking, recalling the battles that were fought 15 years ago to ensure standards of decision making by the Review Boards. It seems clear that the current Ontario government is introducing new personnel to the boards. It is vital to ensure that appropriate appointments are made. These boards are much too important to become the province of political hacks. We have in the last 15 years or so grown to expect a certain standard of decision making from the boards; we must not let that falter.

I want to close by asking some questions about the profession. I was extremely fortunate in the mid-1980s in
having an exceptionally strong array of talented people to introduce me into mental health law. Virtually all have left the field. Sometimes that is for understandable reasons - people are allowed to retire, and people are allowed to change their interests. It is nonetheless difficult to see that it is practical for a lawyer or advocate to build a career in this area over decades. Virtually all of the legal work is legally aided, and in the end, the economics of running a law office create extraordinary pressures to move on to other clients. For the day-to-day work of advocacy, we rely on relatively newly-qualified lawyers.

My Ontario colleagues tell me that there is currently a strong cadre of capable and committed young lawyers representing psychiatric patients. That is encouraging news, but can we expect this situation to last? Ten years ago, at least three of the six Ontario law schools offered courses in civil mental health law. A perusal of law school websites for 2002-2003 shows that only Osgoode offered such a module, taught by a visiting professor from Australia. While there are suggestions that some modules may be re-introduced in the future, it is unlikely that any will be taught by tenured members of staff. This in turn suggests that Ontario law professors do not view mental health law as a core area of their research. My speculations as to how the law is applied earlier in this article may or may not be correct, but perhaps the most telling point is that we as lawyers do not know. The questions are not being asked in the academic literature we read.

This is, of course, systemic of a wider change of interests in Canadian law faculty. A perusal of the job advertisements for law schools makes it clear that issues relating to poverty law are out of fashion. The message is clear: in Ontario we are no longer sexy. This compares unfavourably with the situation in England, for example, where mental health law is increasingly recognized as an academic discipline, with undergraduate teaching on the increase, two major academic journals and a significant number of legal academics actively researching in the area.

All this raises the question of where the next generation of advocates will come from. Financial pressures on young lawyers are set to increase. The decision by the University of Toronto to allow deregulation of law tuition fees is being watched closely by other universities. In part, this is an issue of competition between schools for good students. The illusion is likely to be that paying more means a better education, creating a pressure to increase fees. In part it will be the response of cash-strapped universities, who will feel obliged to charge what the market will bear. Either way, student debt is likely to explode in the near future. That means the practical pressure will be irresistible to leave behind legally aided clients, including those with mental health problems, as quickly as possible: even the new lawyer won’t be able to afford to do that work. This will, of course, be a problem across the board for areas of law involving the poor, and when combined with the lack of status these subjects enjoy in the law school, we have considerable reason to fear for the future of the mental health bar in Ontario.

The result for Ontario is somewhat depressing. If, as I suspect, we see a collapse in the community of lawyers providing services to people with mental health problems, a core part of the combination that made CLIP so successful will have gone. And if attention is allowed to fail, our victories and advances are in jeopardy.

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1 Abella R.S. Access to legal services by the disabled (Toronto: Queen’s Printer, 1983).

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THE EVOLUTION OF MENTAL HEALTH LAW IN ONTARIO

Michael Bay

Psychiatry and the law have been linked for almost two hundred years. In each age, the government of the day has attempted to balance safety and treatment, on the one hand, with autonomy and self-determination, on the other. This exercise is really an attempt at reconciling the irreconcilable and, for this reason, a perfect balance will never be achieved. It seems inevitable, however, that future governments will continue to try their hands at achieving the perfect mix.

In the early 1800s, the British Parliament passed the County Asylums Act, allowing for the establishment of psychiatric facilities. Physicians had full authority over all aspects of institutions and their patients except for admission and discharge, control over which was placed in the hands of the courts. That same system was imported into Ontario and remained in effect until 1933. In that
year, physicians were given full control over those aspects as well. All that was required to forcibly admit a patient was a form signed by two physicians stating that they had examined the person and had satisfied themselves that the subject suffered from mental illness and needed the care available in the institution.

The 1933 legislation was fairly typical for its time, but the winds of change were in the air by the early 1960s. Anti-psychotic medications had been introduced and the enormous psychiatric hospitals of an earlier era had begun to empty. The civil rights movement in the United States had spawned renewed interest in civil liberties and individual autonomy. These factors pushed many jurisdictions in the democratic world to change their mental health legislation in an attempt to respect personal rights and tighten up committal criteria so that a person could only be held if deemed to be a danger to self or others.

By the end of that decade Ontario, too, had gone down the same road, but not until it was prodded to do so by public pressure following a story that played itself out on the front pages of the newspapers. A farmer from the Bruce Peninsula refused to pay his property taxes. When the tax collector came to call, the farmer drove him off the property with a shotgun. The Ontario Provincial Police arrived and, somehow, decided to take him to the maximum-security hospital at Penetanguishene. Once in hospital, the farmer hired a lawyer, who brought an application for habeas corpus. The farmer was released before the court case could resolve, but the story captivated the province and the government of the day hired a young graduate student in law at the University of Toronto by the name of Barry Swadron to write a modern Mental Health Act for the Province. That Act,¹ passed in 1968, only allowed committal on the grounds of dangerousness and created a review board system to provide basic rights protection to patients.

The new legislation did not make everyone happy. By the mid-1970s the Canadian Civil Liberties Association was taking the position that 70% of involuntary patients did not pose a safety risk and were being detained improperly. The government, once again, sought the help of an academic, this time hiring Gilbert Sharpe of the University of Ottawa to rewrite the legislation. Mr. Sharpe proposed confidentiality guarantees for patients and procedural rights at hearings, in addition to tightening up the committal criteria. Notwithstanding protests from certain quarters that it was too rights-oriented, the government implemented the proposals in 1978. These changes were not the last word in the expansion of patients’ rights. In 1985 and 1986, the legislature passed a series of amendments to the Act designed to give patients access to their psychiatric records and bolster their rights in a number of other areas.

By the 1990s, it was clear that it was time to deal with legal issues raised by an ageing population and an increased emphasis on patient autonomy. For the third time, the government turned to an academic. David Weisstub of the University of Montreal, the founder of the International Academy of Law and Mental Health, was retained to conduct a comprehensive study on issues related to consent and capacity. Professor Weisstub and his team of experts produced a report on the topic that is still recognized around the world as the leading work on the topic.

In 1992, the Legislature passed a package of legislation dealing with capacity, consent, adult guardianship, and patients’ rights. Professor Weisstub’s work provided the foundation for the Consent to Treatment Act,² which also borrowed the fundamental principles from the Mental Health Act³ to provide a comprehensive scheme governing capacity, consent to treatment, and substitute decision making in Ontario. That legislation governed all forms of treatment by all health practitioners in all settings in the province. As a result, the consent to treatment provisions in the MHA became redundant and were removed. At the same time, the government brought in modern adult guardianship legislation in the form of the Substitute Decisions Act⁴ and passed the Advocacy Act,⁵ which was designed to provide a voice to consumers of health care by providing advocacy and rights advice services across the Board. The legislative package also abolished the old regional psychiatric review boards and replaced them with the Consent and Capacity Board, with jurisdiction over almost thirty different issues.

Although passed in 1992, these three pieces of legislation were only proclaimed in April of 1995. Within a year, a new government repealed the Advocacy Act and replaced the Consent to Treatment Act with the Health Care Consent Act,⁶ which adopted its predecessor’s fundamental principles while expanding the scheme to cover nursing home admission in addition to consent to treatment.

Over the last 15 years, many jurisdictions across the world have changed their mental health legislation to provide for outpatient committal. Other jurisdictions have amended the committal criteria to allow for involuntary detention on the basis of the need for treatment. By the end of the 1990s, the Ontario government was under intense pressure to bring similar provisions to Ontario. The government once again turned to Professor Weisstub for assistance.

The Legislature adopted a scheme that involves both outpatient committal and a new ground of treatment based on the need for treatment. These provisions, proclaimed in December 2000, are somewhat unique.⁷ The Community Treatment Order rules require a comprehensive plan of treatment as well as consent from a capable patient or the substitute decision maker of an incapable patient. Candidates for an order must meet a tightly established list of criteria. Rights advice is mandatory and the order is reviewable by the Consent
and Capacity Board. The new ground of committal is also designed to only apply to individuals who meet a fairly lengthy list of criteria. An individual may now be held on either or both the dangerousness grounds and the need for treatment grounds.

It is impossible to predict what changes lie ahead. What is certain is that more change will come. The recent amendments mandate a review that will likely take place in the next year or two. That review may result in further changes in the short term. In the longer term, there is no reason to believe that the pendulum will not swing once again. What is certain is that the search for the perfect balance will continue. And that we will never achieve it.

1 S.O. 1967, c. 51.
2 S.O. 1992, c. 31 (CTA), repealed by S.O. 1996, c. 2, s. 2.
7 See generally, MHA, subsections 33.1-33.9.

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A BRIEF HISTORY OF MENTAL HEALTH REFORM IN ONTARIO

Allen G. Prowse * Lyn E. Carpenter†

Since the 1960s, Ontario, like other jurisdictions, has striven to develop a more balanced mental health system that would rely more on community treatment resources than on long-term inpatient care.

In the recent past, starting with The Graham Report (1988), Ontario has attempted to shift human and financial resource investments in the mental health system away from institutions and towards community-based treatment venues. The significant difference between these initiatives and their predecessors has been that they included clear, measurable commitments to monitor progress toward the desired results. These results are at the heart of determining whether and to what extent Ontario’s reform efforts have met their goals.

Key Initiatives and Directions

The history of the most recent reform efforts in Ontario includes the following reports by the province’s Ministry of Health and Long-Term Care (“Ministry”):†

Building Community Support for People: A Plan for Mental Health in Ontario (1988)

Also known as The Graham Report, this document provided an action plan intended to lead to the development of a community-focused, integrated mental health care system in Ontario. A major goal of this plan was to stimulate action to help people with serious mental health problems participate more fully in community life by providing care and support as close to home as possible. It envisioned District Health Councils (DHCs) as the vehicle for bringing together the respective interests of hospitals, community-based services, consumers and their families. With its 19 recommendations, The Graham Report helped launch what proved to be a multi-year provincial process to improve mental health services and supports by funding community-based initiatives such as case management, 24-hour crisis intervention, housing and consumer/survivor and family-run supports. This initial contemporary reform report was followed five years later by a blueprint report designed to advance both the cause and the pace of mental health reform.

Putting People First (1993)

In 1993, the Ontario Ministry of Health published Putting People First: The Reform of Mental Health Services in Ontario. This blueprint for mental health reform provided a policy framework that helped launch the transformation of the province’s mental health services through a planned ten-year mental health reform. This policy framework builds on The Graham Report of 1988. Putting People First helped guide the initiation of a coordinated system of mental health services and supports in Ontario by recognizing fundamental determinants of mental health such as housing, income maintenance, and employment. Putting People First made the following observations about establishing measurable targets and timelines for mental health reform.

To ensure this strategy works, and the system does change, the Ministry of Health has set a number of targets – or critical success factors – that will be used to monitor shifts in service. The targets are tools to assess progress toward the goals.†

This policy framework further noted that:

According to experience in other provinces, setting multiple targets – rather than a single one – and looking at a range of different measures was more just and effective.†

With this overall approach, Ontario established targets for spending, inpatient bed capacity and hospital utilization. The intention was to achieve the following:
1) **Fiscal Shifts:** “By 2003, Ontario will be spending 40% of its budget on institutional care and 60% on community services.”4 To this end, Ontario was to set benchmarks for years one, four, seven, and ten. For the purpose of comparison, approximately 80% of Ontario’s mental health budget was spent on institutional services and only 20% on community-based programs in fiscal 1992-1993.

2) **Bed Ratios:** “By 2003, Ontario will maintain a bed ratio of 30 psychiatric beds for every 100,000 people in the province.”6 In 1992-1993, Ontario maintained an average of 58 psychiatric beds for every 100,000 people, which represented a ratio that was “considerably higher than that in other jurisdictions.”6 The Health Services Restructuring Commission later recommended an interim ratio for adults of 35 beds per 100,000 people. The Ministry of Health and Long-Term Care approved this revised ratio as a target bed ratio and has proceeded with the implementation of these bed targets.

3) **Hospitalization Rates:** If community service enhancements are effective, the hospitalization rate should drop. At the time of printing **Putting People First**, targets for changes in hospitalization rates were in the process of being developed. The establishment of these targets was overtaken by other events and, to date, no target rates for hospitalization have been established.

The intent of these key service ratios and performance measures was to allow government to assess the mix of services, confirm that all key services were being provided and ensure that the right people were getting the services they needed.

In its conclusion, **Putting People First** recognized that “plans, policies and directions [would need to] be developed and refined over the next 10 years”7 in order to make Ontario’s mental health services stronger and more effective.

**Implementation Planning Guidelines for Mental Health Reform (1994)**

This document was one of a series that flowed from the release of **Putting People First**. It focused on the District Health Councils (DHCs) because DHCs were expected to lead the implementation planning process at the district and regional levels. DHCs were seen as an important link with key stakeholders such as consumers, family members, service providers, and interested community members. DHCs were asked to meet the challenge of planning for a mental health system that would put the consumer at the centre of the system. These guidelines were intended to provide the framework within which stakeholders would plan for mental health reform. The guidelines included principles for implementation planning, the roles and responsibilities of the Ministry and the DHCs, and the structures, processes, and resources required to plan for implementation. Several subsequent documents issued by the Ministry in 1995 and early 1996, including **Mental Health Reform Implementation Guidelines for Housing and Support Services** (1995), also supported the DHCs’ efforts in developing implementation plans for mental health reform.

**Rural and Northern Health Care Framework (1997)**

This Ministry document confirmed the government’s vision for health care as meaning “patients getting the right care, in the right place, at the right time.”8 Although there is only one specific reference to mental health programs in this document, it reinforced the basic theme of providing care closer to home.

**Making It Happen (1999)**

The most recently approved policy document designed to provide a structure and approach to guide mental health reform efforts, **Making It Happen**, was published in 1999. This two-part publication (operational framework for services and implementation plan) was to serve as the next step in ensuring that the reformed mental health system would provide integrated and coordinated services that would work effectively for people and were based on best practices. **Making It Happen** offered a strategy to increase service capacity by proposing both an operational framework and an implementation plan that would result in a continuum of care that included providing community alternatives wherever possible. This plan was also intended to guide “strategic reinvestments” to support the implementation of key service delivery changes by 2002-2003. The intent was that “the reformed mental health system would make reinvestment decisions strategically instead of on a program by program basis. Program funding [was to] be directly tied to program performance so that reliance on inpatient services [would be] decreased and the continuum of community and inpatient services [would be] sufficiently funded to meet a diverse range of client needs.”9

**Making It Happen: Operational Framework for the Delivery of Mental Health Services and Supports** outlines three approaches or areas of focus to support effective service delivery:

- service/system accountability;
- shared service models; and
- improved access.

For example, to help address the issue of service system fragmentation (i.e., many separate agencies and many access points), guidelines for common assessment tools and a template for service agreements were proposed. Access improvement would require “each local system of mental health services to develop:

- centralized information and referral functions;
- fewer points of entry;
- consultation services provided by psychiatrists ... be facilitated; and
- minimal assessments”10 – a service system which minimized duplicate assessments.
Making It Happen identified implementation priorities for the Ministry over three years (i.e., 1999-2002). These included:

- tools to facilitate better access – a common assessment tool and a template for service agreements;
- a policy on housing and access to housing;
- an accountability framework; and
- policy frameworks for Schedule 1 general hospitals and physician services.

Making It Happen views consumer need as the key driver towards clear system/service responsibility and accountability. In the implementation plan document, under “Processes/Tools,” the need for an accountability framework to focus on consumer need and service provision is “to be developed.” Ideas on how accountability in consumer service delivery was to be achieved included:

- a minimum data set for performance monitoring;
- negotiated and approved operating plans;
- standardized data-gathering tools (Psycho Social Rehabilitation Toolkit);
- service agreements;
- program standards (such as Assertive Community Treatment Team standards); and
- monitoring and evaluation of reinvestments.

When referring to system management/service delivery responsibility and accountability, the Implementation Plan notes: “Measures of success will include wellness and quality of life indicators, not just symptom reduction. Linking funding to system and program performance is a critical element of system change.” In short, evaluating reform initiatives had stepped beyond broad system targets and was to be achieved by linking funding to outcomes/performance.

Making It Happen committed the Ministry of Health and Long-Term Care to reviewing the Implementation Plan in 2002 and revising implementation strategies and program funding priorities as necessary. In addition, the Ministry’s Mental Health and Rehabilitation Reform Branch committed itself to developing a mental health accountability framework consistent with the direction in Making It Happen. The Mental Health Accountability Framework has been developed and is expected to be released in 2003.

The creation of the Health Services Restructuring Commission resulted in further recommendations for reform. In its February 1999 report Advice to the Minister of Health on Building a Community Mental Health System in Ontario, the Commission recommended that nine Mental Health Implementation Task Forces (MHITFs) be established throughout the province.

The MHITFs were to be responsible for making recommendations to the Ministry of Health regarding the completion of implementation of mental health reform. The nine MHITFs and the Provincial Forum of the MHITFs were established in 2000 and have completed their work, submitting their final reports to the Minister in December 2002. The delivery of these reports sets the stage for the next phase of mental health reform.

Challenges to the Pace of Reform

A number of factors have challenged the pace of mental health reform. There have been both achievements and challenges in its rollout over the last ten years.

Achievements

Since 1995, over $381 million has been invested to advance mental health reform and increase the availability and capacity of services. Among the initiatives undertaken to support the directional change outlined in subsequent Ontario policy commitments such as Making It Happen (1993) and The Newman Report (1998) are a range of actions including: the legislative reforms contained in Bill 68 (Mental Health Reform 2000); expanded access to rights advice; a major homelessness initiative; the funding and establishment of 61 full and partial Assertive Community Treatment Teams (ACTTs); the divestment of six provincial psychiatric hospitals; significant funding for case management and crisis intervention services; and the development of accountability tools, including a specialized transfer payment agreement with the Ministry. Of the total $381 million, over $212 million has been invested in community-based as opposed to institutionally based services. Mental health expenditures in 2001-2002 represented a spending ratio of 56% institutional and 44% community.

Challenges

Events challenge even the best of plans. It has been said that life is what happens when you are making other plans. The following represent key events and time frames which have challenged the pace of reform, have required re-thinking and re-commitment, or have coincided with reduced growth in the community investments needed to complete mental health reform.

- The severe economic downturn of the early and mid-1990s resulted in reduced budget allocations, as government sought to contain expenditure growth.
- The change in government in June 1995 resulted in a re-evaluation of current government directions, including mental health reform. This review ultimately confirmed government’s commitment to continue reform as outlined in The Newman Report (1998).
- Government’s ongoing efforts to reduce and eliminate deficits resulted in controlled allocations and a rate of growth in investment which matched the growth in government revenues. The growth in new community mental health investments matches closely the periods of strong economic growth in the province. The economic downturn
and threat of recession in 2001 caused the pace of investment to decline. These events affected the pace of reform, and serve as an important backdrop for appreciating fully the achievements, which represent significant new investment.

**The Next Steps**

Ontario has made progress in achieving its reform objectives. The dominant community-based mental health system envisioned in *Making It Happen* has not been fully achieved. The completion of the work of the nine Mental Health Implementation Task Forces, the Provincial Forum of Mental Health Implementation Task Forces, and the Forensic Mental Health Expert Advisory Panel, sets the stage for a new wave of reform and a new strategy for action.

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1 Unless otherwise stated, all reports are published in Toronto by the Queen's Printer for Ontario.
2 *Putting People First: The Reform of Mental Health Services in Ontario* (at 28).
3 Ibid.
4 Ibid.
5 Ibid., at 29.
6 Ibid., at 29.
7 Ibid., at 30.
8 *Rural and Northern Health Care Framework*
9 *Making It Happen* (Implementation Plan, at 41).
10 *Making It Happen* (Operational Framework, at 23).
11 *Making It Happen* (Implementation Plan, at 41).

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*Mental Health Reform in Ontario – Where We Are and Where We Need to Go*

Michael Wilson *

The Ontario Government set the course of mental health reform in this province with its strategy, *Making It Happen*, which calls for a mental health system that is “accessible, integrated, comprehensive and accountable.” It then created nine task forces to produce detailed plans of implementation.

For two years, until December 2002, I had the privilege of chairing the Toronto-Peel Mental Health Implementation Task Force and serving as Vice-Chair of the Provincial Forum of Mental Health Implementation Task Forces. Each Task Force was made up of mental health service consumers, family members, service and support providers, business people, physicians, and other community members – the full range of mental health system stakeholders.

People living with mental illness have a right to the same quality of health care as anyone else. They are not receiving it. This must change.

**Putting Consumers First**

Recently, the Honourable Tony Clement, Minister of Health and Long-Term Care, said publicly that successive governments in Ontario have “neglected the mentally ill” for 30 years. The Romanow Commission sounded the same theme nationally when it described mental health as health care’s “orphan child.” At the heart of a reformed mental health system is the conviction that consumers should be at the centre of the system and that every effort should be made to ensure that people living with mental illness get the help they want, when and where they want it.

In a given year, one in five people in Ontario will experience mental illness. This translates to 2.2 million Ontario citizens this year, 330,000 of whom will live with a serious mental illness. Today, however, the mental health system is really no system at all. At best, it is a set of services assembled through successive, relatively ad hoc responses to the needs of Ontarians who face the challenge of living with mental illness. This “system” is egregiously underfunded, hard to understand, severely fragmented and difficult to access. There is little connection and coordination among its various parts. It relies too heavily on Emergency Room and inpatient care. For consumers and their families, it is a bewildering maze.

The treatment and support gap is particularly severe for those who live in poverty, have less schooling, don’t have a job, have an addiction, have other disabilities, or who are members of a racial, ethnic or linguistic minority.

While too little mental health service capacity is a formidable opponent to the development of an organized and responsive system, so is the lack of a system to consistently match consumers to the particular services and supports that they need. Today, some people get more help than they need, and others – many others – get far, far less. Few areas of the province have a comprehensive information, referral or assessment system to guide consumers to caregivers. The result is often poor service, limited and inconsistent levels of coordination.
among agencies and hospitals, onerous duplication and painful frustration for individuals trying to access help of some kind – not knowing what they need or where to turn. Their search too often becomes one of desperation.

The mental health system in Ontario is also plagued by shortages of qualified staff and by insufficient use of evidence-based practices. Even in Toronto, which has one of the highest ratios of psychiatrists and family physicians per 100,000 people in the province, people living with serious mental illness still find it difficult to access their services.

This is not the mental health system envisaged in Making It Happen. Nor is this what people living with heart disease, cancer, or diabetes face. The gaps in Ontario’s mental health care system are arguably the largest and longest-standing in the whole health care system. This too must change.

The Recovery Agenda

Mental health arguably touches every citizen of the province. But the subject is steeped in myth and misinformation. The mythology of mental illness has an iron grip on the way many otherwise logical people perceive the subject. This mythology holds:

- That people living with serious mental illness cannot recover. This is untrue.
- That they are unable to work. Also untrue. And yet 85% of those living with serious mental illness are unemployed.
- That they are violent. One of the most pervasive beliefs, this is also untrue. When provided with the right supports and care, people living with serious mental illness are no more violent than anyone else.
- That consumers are helpless. Spectacularly untrue.

The province’s nine Task Forces believe that the system we must strive for is one that is focused on supporting people’s recovery from mental illness. By recovery, we mean the process by which consumers achieve and sustain a state of well-being – the nature of which must be determined by the individual rather than the system. Recovery is not an end point that one either reaches or doesn’t. Rather, it is a process through which consumers rebuild and further develop important personal, social, environmental and spiritual connections so as to move beyond the devastating effects of their illness and the stigma and discrimination they often experience because of it.

We ask our leaders in government, business and the community to develop a better understanding of mental illness. They must recognize that only one of several critical elements needed to support a person’s recovery is medically-based.

Why is this? Like some other illnesses, mental illness is often chronic and episodic, and support is needed not only from the health care system but also from within the community. Unlike other illnesses, recovery from mental illness is best facilitated when consumers have access to a range of community-based supports that are not usually thought of when discussing recovery from an illness – these include help to secure and maintain a safe, affordable place to live, find and keep a good job, return to and stay in school, and re-establish and form new social connections and friends.

We would not expect someone to successfully battle cancer if they did not have a comfortable home to live in, the ability to take paid time off work for care, and supportive friends and family to stand by their side and help them fight the good fight. However, because of the nature of and the stigma and discrimination surrounding mental illness, these are often the very things that are lost by people living with mental illness, making recovery even more difficult.

In Toronto-Peel, over 90% of the approximately 1000 people we consulted indicated that recovery should be the primary objective of the mental health system. We believe that the promotion of recovery is the ultimate expression of putting the consumer first in the design and delivery of mental health services and supports.

The Leadership Factor

The Task Forces identified a number of themes of action, each of which were tested during our various consultation processes. Some of these themes include the imperative to:

1. Increase service capacity in targeted areas over time so consumers receive the services and supports they want, when and where they want them. Pressing gaps must be addressed immediately, and mental health services and supports must receive their pro forma share of overall health spending increases over time.
2. Create and sustain more housing and housing support, education and job opportunities, and social connection support programs, and address existing challenges for consumer accessing income support programs. In addition to high-quality clinical treatment, these are key elements to support consumers in their recovery in the community, and must be seen and supported as such.
3. Dramatically improve the accessibility of Ontario’s mental health system – for example, through regional information lines and dedicated information and referral services – so consumers and families find it easy to access, exit and re-enter the system as needed. Consumers should be able to access mental health services and supports as easily as any other health service.
4. Enable the system to serve those with especially complex needs by increasing the skills and capacity of both general and specialized service providers, and by strengthening the linkages and coordination between and among service providers, service sectors, Ministries and levels of government.
5. Give consumers and their families an influential voice in shaping and running the system, in part by increasing the capacity of consumer and family initiatives, establishing leadership training programs, and ensuring consumers and families have true seats at all decision-making tables.

6. Achieve greater community and societal understanding of mental illness itself through sustained investment in public education. Stigma and discrimination against those living with a serious mental illness must be eliminated. This is an essential building block for future success.

7. Establish the standards, mechanisms and structures to ensure regional, responsive decision-making, clarity of roles and responsibilities, and greater service and system accountability for outcomes achieved. Decision-making responsibility must move much closer to local communities and to those living with mental illness in Ontario. Consumers and families must be integrally involved in the planning of, allocation of funding to, and evaluation of Ontario’s mental health system. This will result in our being able to better meet consumer needs and ensure accountability for the results achieved throughout the system.

Without leadership, vigilance and courage, this mission will fail as have past efforts by successive governments. From this, we have learned that reform will not just happen. Goodwill alone is not enough. An active and positive catalyst is needed in each region to drive implementation of Task Force recommendations.

Conclusion

Mental health reform is most timely. The Ministry of Health and Long-Term Care spends $2.7 billion a year on mental health services and supports. Mental illness accounts for the longest average length of stay in hospital and for about one-quarter of the 34 million hospital days recorded in Canada each year.

Mental illness in Canada reduces productivity and costs the economy more than $30 billion a year. Untreated mental illness also adds considerable expense to other publicly funded services, as increasing numbers of people with untreated mental illness end up in poverty, in trouble with the law, or both.

And that’s just a snapshot of the economic cost. The human cost is even starker.

Beyond the symptoms and distress caused by a serious mental illness, consumers and families can face discrimination and neglect, unemployment and poverty, incarceration, homelessness and social isolation. The human imperative for change is undeniable.

First and foremost, people living with mental illness have a right to the same quality of health care as anyone else. The Task Forces consulted widely and developed actionable, implementable plans to make this happen. Not surprisingly, though, we all need to commit to work together to make mental health system reform happen. And then the real job begins. Shifting attitudes, changing systemic cultures and – let us not forget this – truly believing in the people that this system is destined to serve.

To face this humbling task, we might draw inspiration from George Bernard Shaw, who once wrote that some see the world as it is and ask why; others see the world as it might be and ask why not. It is they who shape the destiny of humankind.

Why not a mental health system which heals the ache of millions and makes Ontario an even better place to live?

Why not, indeed? Let’s make it happen.


2 Ministry of Health and Long-Term Care memo and subsequent discussion regarding prevalence of serious mental illness.

*CLOSING THE SERVICE GAPS: ASSISTING PERSONS WITH MENTAL HEALTH ISSUES*

The Honourable Mr. Justice Sidney B. Linden *

Clients with mental health issues represent one of Legal Aid Ontario’s (LAO) key priorities. What makes this client group particularly unique is their complex and overlapping social and legal needs. Persons with mental health issues are often deeply affected by legislative and policy changes. The impact of these issues is exacerbated for low-income clients with limited access to other resources and supports. Meeting the needs of this client group present challenges for LAO, but ones we are committed to achieving.

We have worked hard at LAO to ensure that clients with mental health issues are kept at the forefront of our service delivery plans. As Legal Aid moves into its fifth year as a corporation, we have made exploring new and
innovative service delivery methods for persons with mental health issues a focus of our new client service program.

Persons with mental health issues are over-represented in the criminal justice system. An estimated 25% of the 73,000 persons in custody in Ontario are mentally ill. Of these, approximately 9% are considered to have serious mental illnesses. As well, close to half of the people served in mental health court at Old City Hall have no fixed address.

These numbers translate into increasing demand for legal aid assistance. This is evidenced by an almost 60% jump in mental health certificates issued between 1997-1998 and 2001-2002 for representation before the Consent and Capacity Board and the Provincial Guardian and Trustee.

Legal Aid Ontario believes that effectively helping this client group requires a strategic and integrated approach to their multi-dimensional social and legal issues. Currently, we have duty counsel staffing mental health courts; we are funding a pilot project to provide legal services to homeless people; and we are providing funding for test cases that highlight endemic justice system issues associated with persons with mental health concerns.

LAO duty counsel play an integral role in the effective functioning of specialized mental health courts in the criminal court system. The first specialized mental health court in Canada was established while I was Chief Justice of the Ontario Court, in Toronto at Old City Hall in 1998. Although the court was initially set up to deal with fitness issues, the role of the mental health court has expanded over time to include bail hearings and releases, diversion applications and guilty pleas.

Since the beginning of the program, approximately 3000 clients have been assisted by duty counsel in the mental health court at Old City Hall in Toronto.

In my view, the specialized mental health court at Old City Hall is an excellent example of the effectiveness of a multi-disciplinary approach to dealing with the challenges confronting clients with mental health issues. Duty counsel work in tandem with mental health court workers and other mental health professionals to support clients on remand, including making connections with community resources and supporting opportunities for alternatives other than sentencing.

Justice Ted Ormston was one of the driving forces behind the establishment of the mental health court at Old City Hall, and the success of this specialized court has led to similar court programs being launched in other locations. Most recently, a specialized mental health court was set up in Brampton in 2002. New mental health court programs are being considered in other locations and regions of the province. To continue the effectiveness of these programs requires not only judges, crown attorneys, and health professionals, but also legal aid duty counsel with specialized expertise and a commitment to working with clients with mental health issues.

In terms of reaching the high need sector of persons with mental health issues, LAO is funding a project in which a downtown Toronto legal clinic and our Toronto Legal Aid Office is working with four community agencies who deliver services to homeless people to provide direct access to legal aid services. A community legal worker and a staff lawyer attend shelters to provide immediate and ready access to legal services for clients who might not otherwise be able to navigate the justice system. Although the project has been in operation for only six months, it is already at full capacity with over 150 open files.

LAO also has a specific committee that brings to light systemic justice issues through the funding of test cases. The Committee is called the Group Applications and Test Cases Committee (GATC).

GATC and LAO are interested in addressing important justice issues through the funding of test case litigation and representation at coroner’s inquests. Test case litigation also serves as an important tool towards improving the fairness and effectiveness of the justice system for our clients.

Group cases, test cases and coroner’s inquests often raise complex or new legal issues. Therefore, assessing applications objectively and independently is an important function of the committee in determining the merits of and potential benefits these cases may have for low-income Ontarians.

With respect to mental health issues, some of the more high-profile cases LAO funded include: the use of restraints and the training of staff in group homes; a civil action arising from the conditions to which plaintiffs were subjected during the 2002 OPSEU strike; and the constitutional challenge to the failure to proclaim the provisions that limit the length of detention in hospital for offenders found not criminally responsible by reason of mental disorder.

Moving beyond these initiatives, LAO is working more closely with stakeholders such as PPAO to improve our mental health legal services. Currently PPAO assists us in identifying service gaps through LAO’s Advisory Committee on Mental Health Issues. The mandate of this advisory committee is to provide advice to the LAO Board regarding service issues and program improvements to meet client needs. Key among the committee’s recommendations is the recognized need for a comprehensive, coordinated strategy for legal aid services for clients with mental health issues.

LAO is committed to developing legal services that promote a coordinated approach to helping persons with mental health issues. Our strategy in this area will be consistent with our new Client Access and Service Program. This new program will reconfigure our services and resources to ensure consistent access to high-quality
legal services across the province. Specifically, in the area of mental health legal services, LAO will develop a mental health strategy and service plan that will:

- analyze the appropriate mix of service providers and delivery options that best meets client needs;
- work with our stakeholders to develop a strategy to promote the legal rights of clients with mental health issues, including law reform, advocacy, and a test case litigation strategy;
- continue outreach and consultation with community agencies to monitor client needs and LAO services;
- develop an LAO response to proposed legislative amendments to the *Criminal Code* provisions dealing with mentally-disordered accused persons;
- improve support for LAO service providers at the Ontario Review Board, the Consent and Capacity Board, and at specialized mental health courts; and
- develop a quality assurance program for mental health legal aid service providers.

The year ahead for LAO and our partners such as PPAO promises to be interesting, but we have no doubt of our ability to achieve our mutual goals of addressing the needs of persons with mental health issues. Together, we can provide a comprehensive and integrated social and legal network ready to deal with the complex needs of our clients. This will ensure that this most vulnerable group in society receives the right service at the right time and in the right place.

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*Mr. Justice Linden was Chief Justice of the Ontario Court of Justice from 1990 to 1999. He is currently serving as chair of the Board of Directors of Legal Aid Ontario while on leave from the Ontario Court.*

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**POLICE PERSPECTIVES ARISING FROM TRENDS IN THE LONDON POLICE SERVICE CONTACT WITH PERSONS WITH SERIOUS MENTAL ILLNESS**

Lisa Heslop,* Kathleen Hartford,† Ted Schrecker,‡ Larry Stitt,§ and Jeffrey Hoch**

**Objectives**

The Consortium for Applied Research and Evaluation in Mental Health (CAREMH) was established in 1999 to undertake a comprehensive research program on the effects of deinstitutionalization on quality of care and quality of life for individuals with serious mental illness (SMI) in southwestern Ontario. The Consortium represents a partnership among mental health service providers, researchers from the University of Western Ontario, the Lawson Health Research Institute, and the London Police Service (LPS). One element of the research program involved examining changes over time in the pattern of contacts between police and people with serious mental illness and the associated financial costs.

**Methods**

The LPS maintain a database to track events and information related to their involvement with the public. Events are defined as all documented contacts between the police and an individual: occurrences, complaints, street checks and tickets. In order to identify the target population within the police database, contacts with all individuals who appeared in the database were searched for variables identified by the CAREMH investigators as a definite, probable or possible diagnosis of SMI. These variables included:

- Current or previous mental health related addresses (such as Provincial Psychiatric Hospitals or supported housing);
- search terms such as “form 14,” “suicidal,” “Mental Health Act”; and
- three caution flags – “suicidal,” “mental instability” and “mental disability/senile” – which are used by the LPS to identify individuals for internal communication purposes who pose a risk to themselves or to others for a variety of reasons.

Individuals were classified as definite, probable or possible SMI based on these variables. In 1998, there were 92,608 individuals in the general population database. This population was then subset to generate the study population.

Using 1998 as the baseline year, contacts with individuals with SMI were tracked by the research team through to 2001 by the assignment of an innocuous study flag. The number and types of contacts were compared to the contacts with the general population. Charge and disposition data were extracted through a manual search of the police database to determine the types of charges laid and how they related to the various disposition categories.

To complement the quantitative data, officers were interviewed to capture the nature of their interactions with persons with SMI. These interviews were videotaped as the qualitative component of the research project.
Results

Quantitative Results

The quantitative data show that during the study period, 60% of individuals identified in the “definite or probable” categories were charged and/or arrested at least once compared to 31% of the general population in the LPS database. Fifty percent of the “definite” SMI individuals were identified within the police system using the “violent” caution flag. When charge and dispositions for individuals identified in the “definite” category were analyzed over time, charges were less likely to be for violent or property offences in 2000 than in 1998. However, there was a 21% increase in nuisance-type charges, which constituted 61% of all charges laid. Those individuals charged in 2000 were more likely to spend time in jail and were more likely to be fined than in 1998. In fact, 42% of individuals convicted of an offence in 2000 spent some time in custody compared to 34% in 1998. Those receiving fines increased from 9% in 1998 to 20% in 2000.

Almost half (49%) of those individuals identified in the “definite” category were involved in more than 5 events over the study period as compared to 9% of the general population. Between 2000-2001, the LPS had contact with 1084 individuals in the “definite” category. Twenty-five percent of those individuals were re-involved with the police within 4 days. Seventy-five percent had a subsequent contact with police within 269 days and the median time to the next contact was 59 days.

The London Police Service documented a 55% increase in officer time spent in direct response to all SMI individuals over the study period. There was an increase of over 100% in time spent by the Uniformed Division officers. Between 4.1% ($1.5 million) and 11.8% ($3.7 million) of the total London Police budget in 2001 was spent on events involving those individuals identified as “definite or probable” SMI.

Qualitative Results

The quantitative findings validate the subjective experience of the LPS officers as captured during the interviews. Officers emphasized the inappropriateness of using the criminal justice system as a point of access for mental health treatment. They discussed the sense of desperation felt by family members who attempt to initiate a charge in order to obtain assistance for their loved one. While officers have the authority to arrest an individual under the Mental Health Act, they believe that these arrests are often futile because of the admission criteria and limited resources of the hospital where psychiatric services have been centralized. Officers described a “revolving door process,” where they make an arrest under the mental health act based on a sincere belief that the individual is in need of medical care only to have that same person released hours later untreated. The officers believe that such individuals will continue to come into contact with the police because their basic needs are not being met. As more charges are laid and more individuals are kept in custody for minor offences, officers grapple with the implications of having someone in their detention unit who is apparently suicidal or self-injurious. They articulated their limited options in attending to the individuals’ safety.

Recommendations

The first recommendation arising from the findings of this study was to refine the current caution flag system. The large proportion of individuals identified as “violent” is misleading, as it does not correspond with the findings of an actual decrease in violent offences. It could be that officers use the “violent” caution flag to describe behaviour that may be more accurately depicted using other descriptors, such as “agitated” or “confused.” The LPS has begun a review of the possible revisions to this system.

The second recommendation involves enhanced officer training. A proposal to provide enhanced training and skill development has been accepted by the LPS. This training will provide officers with an improved understanding of the major mental illnesses that they encounter and a wider range of intervention strategies. The training will also serve to strengthen linkages with community mental health service providers through increasing officer awareness of referral processes.

Finally, the LPS will explore other means of strengthening partnerships with mental health service providers, such as the use of inter-agency service protocols to ensure a more appropriate, seamless response to individuals with SMI.

Discussion

Borzech and Womrith identify two factors that need to be present to support a theory of criminalization of individuals with serious mental illness. First, individuals with serious mental illness must have a higher incidence of arrest than the general population. Second, an increasing level of contact must occur between the police and individuals with serious mental illness. The key findings of the first four years of this project clearly identified both of these factors – a higher level of arrest, in addition to an increased level of involvement (as measured by more contacts and changes in disposition of those contacts). This evidence supports the hypothesis that individuals with serious mental illness are being criminalized.

The LPS believes that beyond its statutory responsibilities, mental health should not fall within the police mandate; however, substantial police resources are being used in this arena. An analysis of the outcomes of this level of activity, as evidenced in court dispositions and the length of time between police contacts, suggests the need for additional resources and new initiatives to ensure appropriate care and support for individuals with serious mental illness.
Mental Health and Patients' Rights in Ontario: Yesterday, Today and Tomorrow

The Honourable Mr. Justice Edward F. Ormston

Ontario’s first courtroom dedicated exclusively to dealing with mentally disordered offenders opened on May 11, 1998, at the Old City Hall Court House in Toronto.

It had become evident to those working in the criminal justice system that the numbers of mentally disordered accused appearing before the courts were increasing drastically. There were a variety of reasons for this. The number of provincial psychiatric hospitals had been reduced. Alternative housing never materialized. A provincial network of clinics to provide medication and monitor patients was non-existent or inadequate. Homelessness became the most public sign of the problem, while at the same time voters were seduced by politicians who raised the specter of rising crime rates, and more jails and prison were built. The price of mental illness for the homeless became arrest. Jails were the only public institution left open to the homeless mentally disordered 24 hours a day. They were not well served by a justice system seeking efficiency, often falling through the cracks and spending inordinate amounts of time in jail for many offences which were more nuisance than criminal.

A loose coalition of interested parties who experienced this population on a daily basis began to meet. The group included social workers, crown attorneys, defence lawyers, court staff, security, psychiatrists and judges. Eventually a plan emerged. This plan involved the cooperation of the Ministries of Health and Long-Term Care, Attorney General, Solicitor General, Community and Social Services, Corrections, Metropolitan Toronto Police Services and the Centre for Addiction and Mental Health. No new funds were required.

A specific court (102) was provided on a daily basis to deal with mentally disordered accused from Old City Hall and College Park Courts who were in custody and required a fitness hearing before further procedures in the Criminal Code could be triggered. This courtroom had the advantage of adjoining holding cells and office space. This allowed easy access to the prisoner by psychiatrists, social workers, lawyers and families. This also removed the fragile population from the “Bull Pen” atmosphere of the normal cells.

A key feature of the court is the utilization of people with exceptional competence and interest in dealing with the mentally disordered. The court is non-adversarial; the rules of procedure, decorum, and evidence are relaxed. Everyone, including family members and the accused, participates in the dialogue. Psychiatrists are on-site every day to conduct fitness hearings, speak to families and provide advice to the staff.

Specialized duty counsel and crown attorneys staff the court. Judges who have expressed an interest and have expertise in dealing with mentally disordered offenders sit in the court. Other court staff, clerks, security, and assisting officers have attended educational programs on their own time, given by psychiatrists, on how to de-escalate tension in the mentally disordered.

One of the most important components of the court is the on-site presence of Mental Health Court Workers, who facilitate diversion as well as provide a more extensive outreach program to the mentally disordered accused. The Mental Health Court Workers are social workers who have an intimate knowledge of the mental health and social service facilities. They assist the accused in connecting with the appropriate service agencies or treatment centres and follow up any referrals. They also ensure that the accused gets to scheduled appointments and will in general assist with maintaining a higher than usual level of compliance. This aggressive outreach slows down the revolving door phenomenon, which is a conspicuous feature of the mental health system.
Ideally, a mentally disordered accused who is arrested will be identified and sent to the Mental Health Court. He will be seen by legal aid, social workers, and psychiatrists. He will have a fitness hearing immediately followed by a bail hearing. If unfit, a hospital bed will be booked for further assessment or treatment. If fit, the accused will usually be released on bail with terms to deal with risk management, counseling and re-integration. The same procedure applies to those found unfit, once fitness is achieved.

The accused is released from custody and ordered to re-attend court on a frequent basis at first, to monitor and encourage compliance. After a period of four to six months, if the accused is stabilized, reintegrated and has not reoffended, the social workers gather supporting documents and speak to the Crown Attorney about staying the charge or agreeing to a non-custodial sentence if the Crown determines the matter cannot be diverted.

This form of “therapeutic jurisprudence” has at its core a philosophy that most of these offenders are not evil, but ill. It believes that one of the purposes of the justice system is to heal as well as protect. It believes that the accused must be heard and participate in the planning. It believes that positive encouragement, rather than threat, creates a better atmosphere for healing.

The goal of the court is to expedite case processing, create effective interactions between the mental health and criminal justice system, increase access to mental health services, reduce recidivism, improve public safety and reduce the length of confinement in jails for mentally disordered offenders.

The court has dealt with approximately 3000 persons to date. A scientific evaluation has been attempted, but changing circumstances and an unreliable database have hampered it. The empirical feedback has been positive.

The court provides its facilities to the Ontario Review Board upon request. The courtroom is far more convenient for counsel and witnesses and less oppressive for the accused than holding hearings at the jails.

The court is in its fifth year of operation and is facing significant issues and challenges. These include the coordination of treatment for those who have concurrent disorders of mental illness and drug addiction; dealing with the developmentally handicapped; standardizing protocols between the service agencies; and the root problems of lack of housing and poverty.

Should the court be expanded to include the mentally disordered clientele from the other Toronto courts? Should the court include an on-site clinic? Should the court be promoting a “safe house” option for the police, such that the mentally disordered who come in conflict with the law can be brought there, instead of jails or traditional hospitals?

These issues will all be part of the ongoing debate. The court is not perfect, but it is a good start at solving the problems of a mentally disordered person caught up in the criminal justice system.


* The Honourable Mr. Justice Edward F. Ormston, Ontario Court of Justice, Old City Hall, Toronto, Ontario. This article reflects the personal opinion of the writer only.

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MENTAL HEALTH CASES BEFORE THE SUPREME COURT OF CANADA

Anita Szigeti*

In honour of the 20th anniversary of the Psychiatric Patient Advocate Office (PPAO), I am writing to update stakeholders on significant court cases which have advanced the rights of persons with mental health issues. I am a partner in the law firm of HILTZ SZIGETI LLP, which specializes in mental health law litigation. I am also the Chair of the Mental Health Legal Committee (the MHLC), an organization of lawyers who advocate to advance and protect the rights of persons with mental health issues. It should be noted at the outset (with great respect and gratitude) that our legal committee, which now has about a hundred members across the province, was founded by the former legal counsel to the PPAO, David Giuffrida, in 1997. In the intervening six years, the MHLC has contributed a great deal to the development of law and policy in relation to the rights of our clients, dovetailing its work with the important work of the PPAO. Most recently, the MHLC has commenced intervening in those cases proceeding to the Supreme Court of Canada, where our clients' rights are at stake.

In this paper, I focus on two such cases. Oral argument in these two cases in the Supreme Court of Canada was heard on January 15, 2003. We await the Honourable Court's decision with great anticipation. The cases are:

1. *Starson v. Swayze* (a case regarding capacity to make treatment decisions); and
2. *R. v. Owen* (a case regarding a disposition order regarding an NCR detainee).
Background

The members of the MHLC advocate on behalf of clients with mental health issues. We appear daily before the Consent and Capacity Board and the Ontario Review Board in relation to matters of capacity, involuntary admission, reviews of the disposition orders of NCR detainees, and more. The decisions of Ontario’s Court of Appeal in both Starson and Owen, supra, are seminal cases constantly relied upon by members of the Committee on behalf of our clients.

At this moment in time, there is a great deal at stake for persons with mental health issues in Ontario.

Nature of the appeals

Starson v. Swayze

The matter involves Professor Scott Starson, who initially applied to the Consent and Capacity Board for a review of a finding of incapacity about treatment decision-making regarding psychiatric medications. The Board upheld a finding that Professor Starson was not capable to give his own consent to anti-psychotic medications, side-effect medications, and mood stabilizers, among other psychiatric medications. Professor Starson appealed the decision of the Board to the Ontario Superior Court of Justice, which overturned the Board’s decision.

Madam Justice Molloy’s decision in the Superior Court of Justice was appealed by the Respondent physicians to the Court of Appeal for Ontario. The Court of Appeal upheld the decision of Justice Molloy, finding Professor Starson capable in respect of all of the medications proposed. The Court of Appeal decision marks the second time in history that the issue of treatment capacity was considered at this level of Court in Ontario, and the first time an NCR acquittee indefinitely as a result.

The physicians appealed to the Supreme Court of Canada. Leave was granted by the Supreme Court of Canada on April 18, 2002. Intervener status was granted to the Centre for Addiction and Mental Health, the Schizophrenia Society of Canada and the MHLC, as well as the Mental Health Legal Advocacy Coalition (a consumer advocate organization). I appeared by invitation of the Court as Amicus Curiae in the matter.

Issues raised in the Supreme Court of Canada included:

1) Standard of Review

The Appellants argued that the courts below erred in reversing the decision of the Consent and Capacity Board by, in effect, applying a standard of correctness and a strict application of the hearsay rule, rather than a standard of reasonableness, in reversing the findings of fact made by the Board as to the Respondent’s capacity to consent to treatment. They argued that Her Honour unreasonably interfered with factual determinations made by the Board.

2) The Statutory Test for Capacity

The Appellants argued that the Board correctly applied the statutory test in s. 4 of the Health Care Consent Act with respect to the Respondent’s capacity to consent to treatment.

The Appellants argued that the Board reasonably found that Professor Starson was unable to appreciate the consequences of refusing to take the medications proposed, specifically that he would continue detained as an NCR acquittee indefinitely as a result.

On behalf of Professor Starson, the Amicus and interveners supporting the Respondent’s position argued that the Board misapprehended the test for capacity as one in the individual’s best interest and misapplied the test in failing to distinguish between “ability” to understand information necessary for decision making and to appreciate consequences of a decision as opposed to the “failure” to do either or both of these things.

3) Paternalism in the Board

The Appellants argued that the courts below erred in determining that the Board improperly allowed its subjective assessment of, and disapproval of, the choices made by the Respondent to influence its decision.

The argument was advanced that an inability to understand what is in one’s best interest or appreciate the adverse consequences of a decision in relation to treatment is appropriately determinative of capacity.

The Respondent sought to maintain the established principle that capable people have the right to risk and are presumed free to make decisions considered unreasonable where incapable people have the right to informed decision making on their behalf generally in their best interest, where no known prior capable wishes to the contrary exist.

4) Refusal to Admit New Evidence

The Appellants argued that the Court of Appeal erred in refusing to admit new evidence as to events which took place after the hearing before Molloy J. and on the (then) current condition and prognosis of the Respondent.

The argument of the Respondent is that individuals are entitled to a determination of their capacity on the record at the time of the hearing by the tribunal and no fresh evidence in relation to their clinical condition should be admitted (as the Court of Appeal determined.) The significance is the establishing and protection of prior capable wishes to refuse psychiatric treatment.

R. v. Owen

The Court of Appeal heard this matter on appeal from the disposition of the Ontario Review Board and rendered
MENTAL HEALTH CASES BEFORE THE SUPREME COURT OF CANADA

Judgment on May 8, 2001. Leave to appeal to the Supreme Court sought by the Attorney General (Ontario) was granted on July 16, 2002. In 1978, Terry Owen was tried on a charge of second degree murder and found not guilty by reason of insanity. His dispositions provided for progressively increased access to the community, latterly residence in the community under hospital supervision. In January 2000, however, after a urine sample tested positive for cannabis and cocaine, he was returned to inpatient status in the custody of the Kingston Psychiatric Hospital (“KPH”). In May 2000, the Ontario Review Board (“the Board”) ordered that he be detained at KPH with only staff-accompanied access to the hospital grounds or the community. On appeal from that order, the Court of Appeal allowed the appeal, set aside the order of the Board and directed that the appellant be discharged absolutely.

Issues raised included:

1) Standard of Review

Did the Court of Appeal err in concluding that the decision appealed from was unreasonable and could not be supported by the evidence?

2) Interpreting “significant threat to the safety of the public”

Did the Court of Appeal err in holding that the evidence before the Board fell short of establishing that the appellant is a significant threat to the safety of the public, even when using drugs?

3) The Least Onerous and Least Restrictive Disposition

Did the Court of Appeal err in determining that on the evidence before it, the Board could not properly conclude that the appellant posed a significant threat to public safety and was therefore obliged to order his absolute discharge?

Significance of the Cases to Persons with Mental Health Issues

The decision of the Supreme Court of Canada in these two matters is of utmost importance to our clients. Whenever persons with mental health issues come in contact with the civil or forensic mental health system, their basic civil rights and liberty are seriously restricted or entirely removed. The cases of Starson and Owen have significantly affected the way in which Ontario’s mental health tribunals adjudicate cases. Our hope is that their impact will be preserved.

3 Not criminally responsible by reason of mental disorder, pursuant to the mental disorder provisions of the Criminal Code of Canada, Part XX.1.
4 Supra, note 1.
7 Supra, note 2.

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COMMUNITY TREATMENT ORDERS: ISSUES AND EVIDENCE

David Goldbloom*

In December 2000, a revised Mental Health Act,† Bill 68 (also known as Brian’s Law), came into existence in Ontario. Among the changes it included was the introduction of community treatment orders (CTOs), a form of mandatory treatment for a defined subset of people with mental illness living in the community rather than in a psychiatric facility. The introduction of CTOs was extremely controversial and divisive among the many communities that advocate for people with mental illness. At times, the debates generated more heat than light. This chapter will try to illuminate the context in which CTOs entered Ontario mental health legislation, as well as some preliminary evidence regarding their utilization.

The broadest backdrop to this story is the evolution of psychiatry itself from a custodial role in the absence of treatment to a field with effective biological and psychosocial interventions for the reduction of suffering and improvement of broadly defined functioning. For the past 40 years, care has been shifting from institutions to communities, at a pace that may seem glacial at times and with a funding base whose insufficiency would never be tolerated by society for physical diseases. There remains a tension in a caring society between legal rights of autonomy and clinical rights of access to treatment and to health. There is an additional tension between a view that mental health legislation should only sanction intervention to prevent physical danger to self or others and a broader view that preservation of the mind is part of the route to a full autonomy of the person. Bill 68, and CTOs in particular, do not resolve these issues, but rather reflect them.

The introduction of CTOs led to discussion and debate that created strange bedfellows.
psychiatrists who were opposed to the introduction of CTOs were people opposed to any and all coercive treatments in psychiatry and people who repudiated the very idea of mental illness. Psychiatrists in favour of CTOs found themselves supported by people who believed that CTOs would solve problems of homelessness and violence or would obviate the need for further and well-funded mental health reform. More important, however, was the reality that well-informed, well-intended people on either side of this debate held common ground in the goals of:

- optimizing the health, functioning, and quality of life of people with severe and persistent mental illness;
- improving the provision of care in the community to these individuals; and
- reducing the need for prolonged and involuntary hospitalization.

The arguments in favour of CTOs were:

- No feasible alternatives existed in then-current legislation, which was based almost entirely on the provision of hospital-based care.
- CTOs would allow some people with severe and persistent mental illness to remain in the community longer.
- Some research and experiential evidence supported their use in other jurisdictions, notably Saskatchewan and North Carolina.

The arguments against CTOs were:

- They violate the rights and autonomy of citizens living freely in the community.
- Community services are not available to support CTOs, or where they do exist they obviate the need for CTOs.
- The push for CTOs was driven by political rather than health concerns.

The Ontario legislation drew heavily on the experience with CTOs in Saskatchewan since 1995, when they had been introduced by a New Democratic Party provincial government. However, in Saskatchewan, CTOs are applicable only to people who are incapable of making decisions regarding their treatment. The absence of this restriction in Ontario, as well as the legal requirement for informed consent to a CTO by the person subject to it, if capable, or his/her substitute decision maker, has led to an unanticipated result – a significant number of CTOs in Ontario are consented to by the persons subject to them.

Research evidence stems largely from two clinical trials of CTOs in North Carolina and New York City, as well as extensive pre-post implementation studies of CTOs in a variety of jurisdictions, from Australia and New Zealand through the United States (the majority of states have some form of involuntary outpatient treatment) to Israel. A critical review of this data is beyond the scope of this chapter. A detailed critique is available through the Rand Institute for Civil Justice at: www.rand.org/publications/MR/MR1340/; and at www.rand.org/publications/RB/RB4537/. The results are equivocal and the methodological and ethical challenges of research in this area are daunting. One of the inevitable and desired effects of CTOs is the provision of services in the community, and it is difficult to tease apart the benefits of the CTO itself from the benefits of enhanced community services. The most encouraging data regarding CTOs from North Carolina suggests that when they are applied for a period greater than 6 months, they lead to benefits of reduced hospitalization rates, shorter lengths of stay, fewer episodes of violence and arrest, and fewer incidents of victimization. These benefits were experienced by people with schizophrenia but not mood disorder in the group analyses. However, these findings need replication and expansion to understand more broadly the experience and impact of CTOs – on people with mental illness, their families and friends, and the health system.

The requirements for issuance of a CTO in Ontario are, at first glance, at odds with popular perception and understanding. The legislation sets important parameters and restrictions regarding their use as well as mechanisms for appeal. In contrast to the remainder of mental health legislation that governs all Ontarians, CTOs can be applied only to a designated population of individuals who, as a result of their serious mental disorder, have already exhibited a pattern of recurrent hospitalizations that features stabilization followed by discharge, discontinuation of treatment, relapse, and readmission – the “revolving door.” Indeed, the law quantifies the number of days of hospitalization, as a minimum must have already occurred in the previous three years before a CTO can be contemplated. It is not a mechanism for “first-time callers” to the mental health system.

Before a CTO can be issued, a plan for treatment in the community must be developed. This is an important step since the development of a realistic plan for treatment in the community first may obviate the need for the CTO.

While a CTO can be issued on a person currently in the community, the threshold for this imposition is high; the person must be eligible for detention under a Form 1, but instead of being detained at a psychiatric facility, he/she will be treated in the community under a CTO. Since the individual is already at liberty, it makes sense that the bar is set high for any restrictions on that, with the goal of trying to avoid involuntary hospitalization. More commonly, CTOs are issued for people currently in the hospital who are likely to relapse and be readmitted once in the community; in this context, CTOs would serve to shorten the current admission and reduce the rate of readmission.

A further restriction on CTOs is that the person subject to them must be able to comply with the plan for treatment. This raises the obvious question of what is meant by “able to comply”? Does it signify willingness or physical capacity? Recent decisions by the Consent and Capacity Board have indicated the latter.
In addition, the legislation states that the services outlined in the plan must be available in the community. This important requirement conscripts the community to provide the needed services.

Finally, and perhaps most importantly, CTOs require informed consent. This is one of the two most misunderstood aspects of CTOs in Ontario (the other being the actual power that CTOs accord physicians). The Health Care Consent Act\(^1\) has been amended to include community treatment plans as an umbrella term for a treatment requiring informed consent. Despite the non-consensual image of the term “order,” CTOs cannot exist without the informed consent of the person subject to them, if capable, or his/her substitute decision maker. This requirement for consent immediately differentiates a CTO from those powers in the Mental Health Act for involuntary detention in a psychiatric facility.

What does a CTO compel a person subject to it to do? Contrary to some perceptions, it does not give anyone the authority to physically force an individual to comply with the treatment outlined in the CTO. While the legislation states the person must comply with the treatment plan, what is at issue is what happens if the person does not comply. This may result in the one directly coercive power of a CTO: the physician may issue an Order for Examination, which authorizes the police to apprehend the individual and bring him/her to the issuing physician for a psychiatric evaluation to determine one of several articulated outcomes:

- The person should be placed on a Form 1 and detained for assessment.
- A new CTO (presumably with different requirements) should be issued with the consent of either the person, if capable, or his/her substitute decision maker.
- The person should be released without a CTO.

Viewed in this context, the powers of the CTO are limited. First, the physician is not obliged to issue an Order for Examination after non-compliance (which could be as little as a single missed appointment or a single dose of medication omitted) but may choose to do so (more likely for more significant non-compliance). However, even if the physician wishes to issue an Order for Examination, he/she may only do so after a number of pre-conditions are met regarding trying to locate the individual and inform him/her of the non-compliance and potential consequences, as well as offering to assist the person in complying.

To what extent are CTOs being implemented in Ontario? It is unfortunately difficult to document this accurately, although the requirement for rights advice prior to issuance of a CTO provides one measure, in the extent to which that advice is provided by the Psychiatric Patient Advocate Office (PPAO) across the province. The absolute numbers need to be placed in a context. There are approximately 8 million people in Ontario aged 18 and over. Based on 1% prevalence estimates of schizophrenia, approximately 80,000 Ontarians suffer this illness.

In 2001, approximately 110 CTOs were issued across the province, suggesting use for 0.1% of Ontarians with schizophrenia, and an even lower percentage if the eligible population is expanded to include other major psychiatric disorders.

From January to December 2002, the PPAO reported that rights advice was delivered regarding 266 new CTOs and 96 CTO renewals (they expire after 6 months) for a total of 362 CTOs contemplated across Ontario (because rights advice is required prior to actual issuance of a CTO, it is impossible to know how many were subsequently issued; further, these numbers do not include CTOs in those 17 Ontario Schedule 1 psychiatric facilities that do not use the PPAO for rights advice service). More than 50% of people on these CTOs had been deemed capable of consent to them. Data from the Consent and Capacity Board in Toronto indicates that fewer than 20 have been subject to review through the available appeal mechanism.

A number of important clinical and research questions must be addressed to understand the impact of CTOs on Ontarians and to prepare for the upcoming mandatory review of the Mental Health Act itself:

- What have been the broadly defined advantages and disadvantages for people with mental illness with regard to access to and benefit from treatment, therapeutic alliance, quality of life and functioning, and utilization of traditional involuntary or voluntary inpatient services?
- What has been the impact on families, friends, community and hospital service providers, and the police?
- Why have so many individuals provided their own consent for CTOs? What is their understanding and perception of its powers and obligations? What is their perception of coercion?
- What is the impact on access to community services for people who are not placed on a CTO? Is there queue-jumping in the context of short supply?

These are some of the challenges in understanding that are facing us. The introduction of legislation with CTO provisions has spread broadly across Western democracies in the past decade and is above and beyond any immediate clinical, legal, or political exigencies in Ontario. However, we owe it to all our citizens to evaluate carefully and broadly the impact of CTOs in our continuous juggling act of values of liberty and health.

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\(^{2}\) S.O. 1996, c. 2, Sched. A.
MENTAL HEALTH:
AN EVOLVING AREA OF LAW

Mary Jane Dykeman

The 20th anniversary of the Psychiatric Patient Advocate Office (PPAO) provides a welcome opportunity to reflect on mental health as a discrete branch of health law and policy. For both lawyers and policy-makers, mental health is a rich and diverse field, one that encompasses broad and complex legal, social, and ethical issues. The human element is also a constant in mental health. In many areas of law, there is no obvious or appreciable consequence to individuals, whereas decisions made in relation to one's own or someone else's mental health have a tremendous and often immediate impact.

Mental health law is by no means an 'emerging' field, to the extent that its evolution has roots in the consumer movement of decades past. Since that time, however, it has been given increased recognition and priority by governments, the health sector, and the public. This paper explores some of the developments that have moved mental health reform forward at both the legislative and systems levels. It takes the position that even as long-awaited mental health reform unfolds, the need for advocacy and public education on a range of legal and ancillary issues is ongoing.

The advent of the Canadian Charter of Rights and Freedoms marked a new era of mental health rights and responsibilities, for both consumers and health care providers. For example, the Charter's section 15 equality rights, which prohibit discrimination on the grounds of a number of factors including mental disability, create additional protections for individuals suffering from a mental illness. Provincial human rights legislation such as Ontario's Human Rights Code also provides an oversight mechanism for individuals who face discrimination in the context of services, goods and facilities; accommodation; and the opportunity to contract on equal terms. These protections are available to everyone, regardless of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, age, marital status, same-sex partnership status, family status, disability or the receipt of public assistance.

In the context of mental health, the section 7 Charter protection of life, liberty and security of the person has traditionally been interpreted as upholding an individual's right to refuse treatment of a mental illness. Grounded in the notion of the right to self-determination, “... to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.”

More recently, section 7 of the Charter has been interpreted by some authors, including Gray et al., from a 'human needs perspective', whereby the liberty component of life, liberty and security of the person supercedes the security interest of the individual. The argument is premised on the theory that if left untreated, persons suffering from mental illness will have no option but to remain institutionalized, potentially for the rest of their lives. The argument has been made that this result is contrary to a true liberty interest. Instead, the authors promote a treatment model that would leave the individual free to reside in the community as long as he or she agrees to accept treatment of his or her mental illness. They acknowledge that this is in sharp contrast to the purely "civil libertarian" arguments against compulsory treatment which have been adopted by other prominent Canadian authors writing in the areas of mental health law and policy. To date, the human needs position as advocated by Gray et al. has neither been argued before, nor affirmed by, the courts in Canada, and the security of the person continues to be enshrined in case law and in statutes such as Ontario's Health Care Consent Act.

A recent landmark case, which has made its way to the Supreme Court of Canada, Starson v. Swayze, did not turn expressly on the issue of compulsory treatment. Instead, it focused on capacity to consent to treatment as set out in the HCCA:

4(1) A person is capable with respect to treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

As well, it examined the standard of review applied at the trial level by Molloy J. with respect to the Consent and Capacity Board's decision that Professor Starson was incapable of consenting to mood stabilizers and with anti-psychotic, anti-anxiety and anti-parkinsonian medication. The Starson decision, which was heard by the Supreme Court of Canada on January 15, is eagerly anticipated.
At law, there are very few exceptions to the right not to be treated without the consent of the individual or his or her substitute decision-maker. The federal mental disorder provisions, Part XX.1 of the *Criminal Code of Canada* state that if an accused is found unfit to stand trial, he or she may be treated for a limited time period with the view to rendering him or her fit:

672.62(2) The court may direct that treatment of an accused be carried out pursuant to a disposition made under section 672.58 without the consent of the accused or a person who, according to the laws of the province where the disposition is made, is authorized to consent for the accused.

A second circumstance in which treatment may be administered without individual consent does not relate directly to treatment of a mental illness, but instead, applies to the identification and control of infectious disease in order to protect public health. Where an individual fails to comply with an order of the medical officer of health with respect to a virulent communicable disease, section 35 of the *Health Protection and Promotion Act* permits compulsory examination and treatment outside the parameters of HCCA.

The December 2000 amendments to the *Mental Health Act* included the creation of a community treatment order (CTO) scheme with a stated purpose of providing “…a person who suffers from a serious mental disorder with a comprehensive plan of community-based treatment or care and supervision that is less restrictive than being detained in a psychiatric facility”. A common misconception is that CTOs constitute compulsory treatment. In fact, they require the consent of the individual or substitute decision-maker, and rights advice must be provided to each where applicable. There was considerable discussion among stakeholders in the months leading up to the enactment of these amendments, though, as to the nature of the consent obtained, if the only alternative to treatment is being made an involuntary patient in a psychiatric facility.

From a risk management perspective, the MHA contains an elaborate maze of procedural requirements for physicians, health facility senior management and staff. With the exception of community treatment orders, the MHA applies exclusively to care provided in a psychiatric facility. It sets out numerous duties of the “officer-in-charge”, who by definition is the officer who is responsible for the administration and management of a psychiatric facility. At the time of writing, the MHA counted no fewer than 165 references to the officer-in-charge. While some of these are merely descriptive, a majority of these provisions are substantive, and require vigilance to ensure that the officer in charge is in compliance with the Act. This should be done as a best practice, and not only because failure to comply with these statutory requirements has in the past formed the basis of challenges to the Consent and Capacity Board. While some are of the view that the MHA is unduly onerous and pits health care providers against their patients, until such time as these substantive requirements are changed, due diligence should prevail.

A final area of the MHA that represents both forward thinking and the need for further change are its provisions with respect to disclosure of and access to the clinical record. These provisions, which include protections against the disclosure of a person’s mental health record in proceedings, have been seen over time by privacy advocates to have set a high bar for the safeguarding of one’s own health information. What is missing, however, is a similar framework for community-based services, particularly in light of the divestment of provincial psychiatric facilities and provision of community mental health services and supports. In practice, this means that individuals residing in the community who avail themselves of necessary mental health services will not have the same protections as those who are voluntary or involuntary patients in a psychiatric facility. It also has implications for patients who are discharged into the community, and for community agencies, which have legitimate reason to share information to optimize available services. At a time when much effort is being expended to integrate mental health services, this gap may serve to undermine the seamless delivery of care.

The myriad of issues that make mental health a very complex and rewarding area in which to practise law and create policy is increasing. When combined with the compelling legal issues they raise, many (such as affordable housing, meaningful employment, access to new drugs, public education to reduce stigma about mental illness, and equitable access to mental health services and supports regardless of geographic location) continue to require advocacy at a number of levels. The 20th anniversary of the PPAO should be viewed as a time to pause and reflect on how far many of these issues have progressed, with collective minds turned to future opportunities for positive change.

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4 Charter, supra, note 1, s. 1.
8 This case became *Fleming v. Starson* at the Supreme Court of Canada. The case is discussed more fully in this anthology by Toronto lawyer Anita Szigeti of Hiltz Szigeti LLP, who acted as amicus curiae to Professor Starson at the Supreme Court.
11 35(5) In an order under this section, the judge may order that the person who has failed to comply with the order of the medical officer of health, (a) be taken into custody and be admitted to and detained in a hospital named in the order;
The rights of patients appearing before the Ontario Review Board have been expanded significantly in the last two decades. The rights gained have been recognized by the Supreme Court of Canada as constitutionally protected rights. The constitutional protection of the rights of patients before the Ontario Review Board derives from the involvement of the patient in the criminal justice system. Development of jurisprudence on the issue of the rights of the mentally ill in the criminal justice system progressed steadily following the enactment of the Canadian Charter of Rights and Freedom in 1982. While prior to 1982, the Law Reform Commission had made extensive recommendations for reform, those recommendations were largely ignored until the courts mandated reform. The reluctance of governments to act on long-standing criticisms of the system has been a consistent theme over the past two decades and arguably for the past two centuries. Therefore litigation of the rights of the mentally ill offender remains critical to the protection of mentally ill persons ensnared in the morass of the criminal justice system. This paper will focus on the gains of the past two decades and the remaining unresolved issues facing accused persons before the Board and their advocates. It will put those gains in historical perspective by examining the foundation of the current system in the common law.

Historical Perspective

The Origins of the Legislative Scheme

In 1800 in Britain, James Hadfield, a mentally ill man, was tried for high treason as a result of his attempt to kill King George III. The lack of any alternatives to prison for mentally ill offenders was the subject of judicial consideration and condemnation. In response, British parliament passed the Act for the Safe Custody of Insane Persons Charged with Offences (c. 1800). The Act provided:

...if [the jury] shall find that such person was insane at the time of the committing of such offence, the court before whom such trial shall be had shall order such person to be kept in strict custody, in such place and in such manner as to the court shall seem fit, until His Majesty's pleasure shall be known; and it shall thereupon be lawful for His Majesty to give such order for the safe custody of such person, during his pleasure, in such place and in such manner as to His Majesty shall seem fit...

This portion of the Act was incorporated into the draft Criminal Code in Britain, which was never passed into law in Britain but became the Criminal Code in Canada. The section of the Criminal Code of Canada dealing with the “safe custody” of “insane” offenders remained unchanged from the 1800 British version for almost two centuries, except to substitute His Majesty’s representative, the Lieutenant Governor, as the person who determined the place and manner of detention. The 1991 Criminal Code provided that:

Where the accused is found to have been insane at the time the offence was committed, the court, judge or magistrate before whom the trial was held shall order that he be kept in strict custody in the place and in the manner that the court judge or magistrate directs, until the pleasure of the lieutenant governor of the province is known.

In 1982, a patient detained pursuant to a warrant of the Lieutenant Governor was interviewed by the Board psychiatrists and sometimes by the other Board members, in camera, without counsel. Counsel for the patient had no right of access to the hospital report or files. Counsel had no right to cross examine witnesses, nor did the accused. Essentially, the role of counsel was to call witnesses and to make submissions. Not an easy task in
light of his/her effective exclusion from one of the most significant portions of the hearing and his/her inability to challenge through cross examination the case against the accused. The Court of Appeal in Re Abel et al and the Director, Penetanguishene Mental Health Centre found that the Board was under a duty to act fairly but interpreted that duty not as a requirement to provide specific facts but merely the “substance” of the facts upon which the Board is going to “apply its mind.”

It should be noted that the Law Reform Commission in 1976 criticized the LGW system and recommended significant reform of the system. No legislative changes resulted from these recommendations, even after a Department of Justice discussion paper, released in 1982, described the mental disorder provisions of the Criminal Code as “fraught with ambiguities, inconsistencies, omissions, arbitrariness, and often a general lack of clarity, guidance or direction. The paper, like the Law Reform Commission report six years earlier, identified the potential unfairness of the automatic detention of mentally ill offenders and the indefinite detention of unfit accused without the Crown showing a prima facie case.


In R. v. Swain in 1986, the entire Lieutenant-Governor’s Warrant scheme was challenged as being contrary to the principles of fundamental justice. In particular, the automatic detention of an accused upon a finding of not guilty by reason of insanity was argued to be unconstitutional. The Court of Appeal for Ontario rejected the argument, but Brooke J.A. wrote in dissent:

To sentence the appellant to be held in strict custody until the Lieutenant Governor’s pleasure was known, was to deny him his liberty in a way that did not accord with the principles of fundamental justice.

In 1991, the Supreme Court of Canada struck down the impugned sections but gave parliament six months to amend the legislation. R. v. Swain and the resulting 1992 Mental Disorder Provisions of the Criminal Code have solidified the gains of the previous decade of Charter litigation and provided the basis for further advances in the rights of accused under the Criminal Code and Charter.

1992: Winko

The legislative changes introduced by Part XX.1 of the Criminal Code in response to R. v. Swain were sweeping and fundamental. The slow incremental changes brought about by procedurally complex and time-consuming judicial review were overtaken by a comprehensive scheme which at least to some extent codified procedural safeguards for the patient. The legislation provides for the appointment of counsel wherever the interests of justice so require and in every case where the issue of fitness to stand trial is raised. Thus, the assistance of counsel has become the rule rather than the exception. The Part also codifies the requirement of notice to the accused of the material to be relied upon by defining disposition information and requiring that the disposition information or written reports be disclosed in a timely fashion, subject to some narrow exceptions. Timelines are set out for initial hearings and reviews. An appeal process was created directly to the court of appeal for the province and on an expedited basis.

One fundamental substantive change made by Part XX.1 was the articulation of a test for a discharge without conditions. Section 672.54 provides that:

Where a court or Review Board makes a disposition pursuant to 672.45(2) or section 672.47, it shall, taking into consideration the need to protect the public from dangerous persons, the mental condition of the accused, the reintegration of the accused into society and the other needs of the accused, make one of the following dispositions that is the least onerous and least restrictive to the accused:

(a) where a verdict of not criminally responsible on account of mental disorder has been rendered in respect of an accused and in the opinion of the court or Review Board the accused is not a significant threat to the safety of the public, by order, direct that the accused be discharged absolutely;…

The legislation did not provide for an onus of proof on the issue of dangerousness. Immediately following the passage of C-30, the British Columbia Court of Appeal interpreted this section in Orlowski v. British Columbia (Attorney General). The court held that if the Board or court could not resolve the issue of the dangerousness of the accused, the accused must remain subject to a disposition. If the Board was unable to find affirmatively that the accused was not a significant threat to the safety of the public, the accused would not be absolutely discharged. This test was applied across the country from 1992 until overruled by the Supreme Court of Canada in Winko v. British Columbia. In Winko it was held that absent a finding that the accused represents a significant threat to the safety of the public, there can be no constitutional basis for restricting his or her liberty.

Winko had a profound effect on the number of accused who left the system. The proclamation of Bill C-30 caused no change in the number of absolute discharges granted. Following the decision Winko, however, the percentage of absolute discharges granted in relation to the number of the accused in the system doubled (6.6% in 1993 to 13.8% in 2000). Apart from the concrete result of ensuring that no onus is placed on the accused to prove that he or she is not dangerous, Winko articulates a philosophy in dealing with the mentally ill offender that will not countenance reliance on stereotypes about “dangerous” mentally ill
By creating an assessment-treatment alternative for the mentally ill offender to supplant the traditional criminal law conviction-acquittal dichotomy, Parliament has signalled that the NCR accused is to be treated with the utmost dignity and afforded the utmost liberty compatible with his or her situation. The NCR accused is not to be punished. Nor is the NCR accused to languish in custody at the pleasure of the Lieutenant Governor, as was once the case. Instead, having regard to the twin goals of protecting the safety of the public and treating the offender fairly, the NCR accused is to receive the disposition “that is the least onerous and the least restrictive” one compatible with his or her situation, be it an absolute discharge, a conditional discharge, or detention.

In summary, the purpose of Part XX.1 is to replace the common law regime for the treatment of those who offend while mentally ill with a new approach emphasizing individual assessment and the provision of opportunities for appropriate treatment. Under Part XX.1, the NCR accused is neither convicted nor acquitted. Instead he or she is found not criminally responsible by reason of illness at the time of the offence. This is not a finding of dangerousness. It is rather a finding that triggers a balanced assessment of the offender’s possible dangerousness and of what treatment-associated measures are required to offset it. Throughout the process the offender is to be treated with dignity and accorded the maximum liberty compatible with Part XX.1’s goals of public protection and fairness to the NCR accused.

These principles should be seen as guiding the interpretation of the statute. McLachlin J. in interpreting subsection 672.54(a) stated that it must be read in the context of the preamble which stipulates that the Board must make the order that is the least onerous and least restrictive. She also points out that it must be read against “the constitutional backdrop that public safety is the only basis for the exercise of the criminal law power absent a conviction”.

Post-Winko: Unresolved issues

The test for conditional dispositions

One might have thought that the broad interpretative direction enunciated by McLachlin C.J.C. would provide guidance to the lower courts in interpreting the test to be applied in fashioning conditional dispositions. The vast majority of hearings before the Ontario Review Board result in a disposition that includes conditions. Following Winko, several Board decisions used the test set out in the preamble to section 672.54 as the test for determining the nature and extent of community access as defined by a conditional disposition.

The proposition that this is the appropriate test to be applied to conditions in a disposition has however been consistently rejected by the Court of Appeal for Ontario. Before Winko was decided, the Court of Appeal considered the issue in R. v. Pinet. The Court of Appeal decided that the Board in detaining a person may specify the hospital and level of security as part of its jurisdiction to impose conditions but need not do so. The court further held that where the Board saw fit to impose conditions including the level of security, the criteria in the preamble to section 672.54 should not determine the conditions. Rather, the Board or court should determine whether the conditions are appropriate. At page 102 the court stated:

It was argued in Penetanguishene Mental Health Centre v. Ontario (Attorney General) and Tulikorpi that Winko implicitly overruled Pinet and that “least restrictive, least onerous” applies to conditions imposed under 672.54 (b) and (c). The Court of Appeal rejected that position. It did so on the basis that: 1) Pinet is not even mentioned let alone explicitly overruled in Winko; 2) When McLachlin J. refers to the least onerous least restrictive test in Winko she does so in the context of the three categories of dispositions; and 3) Winko stopped short of advocating that the least onerous, least restrictive test should be applied to conditions.

However, in Tulikorpi, Moldaver J.A., while following Pinet, invited the Supreme Court of Canada to consider the issue of whether least onerous and least restrictive should apply at least to the condition that specified the hospital or level of security.

Since Tulikorpi, there has been a subtle and perhaps unintended shift in the position of the Court of Appeal. In R. v. Pinet (#2), the court, while affirming the position that the Board need not impose the least onerous, least restrictive conditions, stated that the relevant considerations for the Board in imposing conditions were the four factors set out in the preamble to 672.54.

Conclusion

Conditions are the lifeblood of the dispositions. There is no principled reason to separate the conditions from the disposition and to apply a different test to the imposition of conditions.

The test that best meets the goals of Part XX.1 and is consistent with the principles enunciated in Winko is one wherein the court or Review Board is required to make a disposition – including conditions – that is the least onerous and least restrictive to the accused, taking into account the need to protect the public from dangerous persons, the mental condition of the accused, the
reintegration of the accused into society and the other needs of the accused. It is not helpful to separate the conditions from the disposition and to apply a separate test to each. The disposition should be viewed as a whole and the conditions as an integral part of the whole. Different aspects of the disposition may address different factors from section 672.54. Each condition viewed separately may not address each factor. If, however, the disposition, including the conditions, addresses the necessary factors and grants the accused the maximum liberty consistent with the safety of the public, the Board will meet the goals set out by the Supreme Court of Canada in *Winko*.

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1 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), c. 11 (Charter).

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THE ONTARIO OFFICE OF THE PUBLIC GUARDIAN AND TRUSTEE: KEY PRINCIPLES AND RELATED CHALLENGES

Trudy Spinks*

The Role of the Office of the Public Guardian and Trustee

The Office of the Public Guardian and Trustee (OPGT) congratulates the Psychiatric Patient Advocate Office (PPAO) on its 20th anniversary. The positive working relationship that has developed between the OPGT and the PPAO has, we believe, contributed to the success of both programs. Like the PPAO, our office has seen a dramatic increase in the scope of the services provided over the past 20 years, in addition to a need to adapt to continuous change in the legislative, operational, and governmental environments within which our vulnerable clients are served.

Over this period, the role of the OPGT has evolved from a narrow mandate, which focused primarily on safeguarding the finances of patients in psychiatric facilities to an organization which serves a diverse group of mentally incapacitated people through a variety of programs.

For example, the OPGT now has a role in making substitute decisions when non-emergency treatment or admission to long-term care is proposed for a person who is mentally incapable and who has no one else who is available, capable, or willing to take on this responsibility. This program area – the Treatment Decisions Unit – also recently acquired the role as decision-maker of last resort for Community Treatment Orders made under the *Mental Health Act*. PPAO staff are involved in many of the Unit’s referrals in their capacity as rights advisors.

The OPGT also operates a program mandated to investigate reports that an individual who lacks capacity is at risk of serious harm. These investigations will result in the OPGT seeking guardianship through the court, providing that incapacity and serious risk is established, there are no other appropriate solutions, and guardianship could provide real benefit in the circumstances. This program is intended to address complex situations requiring long-term decision-making. It is not, given the scope and complexity of the investigation and court process, an emergency crisis intervention service.

Another program area provides substitute decision-making for people involved in legal actions who are found by a judge to be unable to understand and appreciate the issues sufficiently to instruct their counsel or make the necessary decisions throughout the proceeding. Most of these people are not represented by the OPGT in any other capacity.

The OPGT continues to serve the original mandate of the Office, which involves providing financial guardianship for incapable adults. There are currently over 9000 incapable people throughout Ontario whose finances are managed and protected by the OPGT in the absence of anyone else who is willing and suitable to assume this responsibility. Approximately 1800 new financial guardianship clients are assigned to the OPGT each year. The majority of these clients are incapacitated mentally and there are no other appropriate solutions. Both *Tulikorpi* and *Pinet* have been granted leave to appeal to the Supreme Court of Canada in the spring of 2003.

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are assigned to the OPGT from Schedule 1 facilities and thus many of our new clients receive advice through the PPAO about their right to appeal the finding of incapacity to the Consent and Capacity Board. Guardianship for personal care is also assigned to the OPGT by the court on rare occasions. These are always contentious cases involving high risk and invariably involving numerous parties, protracted legal proceedings, and unusually challenging decision-making.

Key Principles and Related Challenges

There are certain fundamental policies and principles that the OPGT applies consistently in all its programs which serve incapable adults. Although the number and scope of these are too broad to cover in an article of this length, a brief description of some of them and the associated issues and challenges is as follows:

1) *Intervention by the government in an individual’s private life is a last resort step to be undertaken only when there is clearly no suitable support available from family and friends and no less intrusive way of protecting the individual.*

The continuing attempt to maintain the balance between the competing values of autonomy and protection is an ongoing challenge for the OPGT. This is particularly so in relation to the investigation function, as the investigation powers and process are, unavoidably, quite intrusive. It is also common for adults for whom an investigation has been undertaken in response to allegations of risk be extremely resistant to the intervention. Family members and “friends,” who are not infrequently the alleged abusers, often become extremely adversarial.

Given that the same situation usually involves caregivers or community agencies who are most anxious that the OPGT take prompt protective action, the result is frequently a situation of intense conflict between the various parties with competing views attempting to influence the outcome. In addition, because the information obtained during the investigation cannot be disclosed to any of the parties due to confidentiality rules, the rationale for the OPGT’s decision to close or proceed in a guardianship investigation is not fully understood by those who disagree with the outcome.

Since the inception of this program in 1995, the OPGT has developed experience and expertise in dealing with these issues and balancing the interests of the adult’s autonomy and social relationships, on the one hand, with the paramount goal of protecting him or her from serious harm, on the other.

2) The best interests of the incapable client for whom the OPGT is substitute decision-maker are paramount in all decision-making. Although this principle – which is consistent with the statutory requirements of the *Substitute Decisions Act, 1992* and the *Health Care Consent Act* – would appear to be self-evident, it is surprising how poorly understood it is by many of those with whom the OPGT interacts for its guardianship clients. It is quite common, for example, for third parties to advocate strenuously for their own interests to be accommodated by the OPGT at the expense of the interests of the incapable adult.

As a result, one of the major challenges for the OPGT in serving its vulnerable clients is the continuous effort to educate those involved in the client’s affairs about the OPGT’s legal duty to protect and advocate for its clients, notwithstanding that this may place the Office in conflict with the interests of others.

Deciding what is in the client’s best interest in any given situation is also often a challenge for the OPGT when there are many competing facts and values at issue. This is especially so when the OPGT is guardian of finances and the obvious financial advantage of a particular decision is offset by a negative impact on the client’s family or extreme opposition from the client. In trying to resolve these issues, the OPGT takes the view that financial decisions must be assessed in reference to the overall context of the person’s life and that the client’s relationships, history, and current wishes must be factored in when determining “best interest” in the financial context.

3) *In acting as substitute decision-maker in any capacity, the OPGT will maintain as much ongoing contact with the client, his or her supportive family, friends, and caregivers as is possible in the circumstances.*

The OPGT recognizes that its clients have varying abilities to participate in the decision-making process and that the ability to serve the client effectively and make informed decisions requires personal contact with the client and those involved with the client.

Regionalized service delivery has significantly enhanced our accessibility and many clients and service providers attend our regional offices to discuss issues with staff or to receive funds directly.

Staff also visit their guardianship clients a minimum of once per year. Clients who are able to articulate wishes about their budget and handling of their assets are consulted, as are family, friends, and caregivers who are willing to be involved and who have demonstrated support for the client. Investigation and treatment decisions staff are also in regular contact with clients and their service providers.

4) *The OPGT has an important role in educating the various stakeholders involved with incapable adults about the legislation, process, and practical
considerations in dealing with issue relating to incapacity.

It is widely accepted that the legislation (Substitute Decisions Act, Health Care Consent Act, and Mental Health Act) and the way that all the services for incapable adults operate and interact, are highly complicated. The public and the legal, health, and service sectors report ongoing challenges in understanding the complexities and technicalities of the law and related systems.

The OPGT has assumed a leading role in the ongoing education of stakeholders about these topics and about the mandate and functions of the OPGT itself. Considerable time and resources are devoted to the provision of education about the way the statutes work, the way substitute decision-makers are appointed, and the interplay between various components of the system such as the OPGT, PPAO, health practitioners, service providers, legal counsel, CCAC, courts, and the Consent and Capacity Board. Over 100 outreach sessions are provided by OPGT staff annually on these topics.

Recently, a key focus of the Office has been the education of Schedule 1 facilities about Part III of the Mental Health Act. This part sets out the rules that must be followed in assessing new in-patients for capacity to manage finances and in completing related documentation. It has been the OPGT’s experience that the mandatory nature of these rules and the very serious consequences of non-compliance are not well understood. The OPGT has circulated material which provides a step-by-step explanation of the required processes and the Office continues to provide outreach to Schedule 1 facilities on an ongoing basis.

Another focus of our outreach efforts involves explaining to other service providers what the OPGT’s role is when it manages a client’s finances and property. As guardian of property, the OPGT makes financial transactions, authorizes spending and makes financial decisions on the client’s behalf. It does not, however, provide social work services or other services of a personal nature. Identifying for others the point at which the “financial” element ends and the “personal” begins is a continuing challenge, especially since most issues in life have elements of both.

The OPGT has also developed written guides and brochures which include:

- Guide to the Substitute Decisions Act
- When the Office of the Public Guardian and Trustee Becomes Your Guardian of Property
- Guardianship Investigations – the Role of the OPGT
- Providing Property Guardianship Services – the Role of the OPGT
- Becoming a Guardian of Property – Information for Family Members and Friends
- The Role of the OPGT in Making Substitute Health Care Decisions
- Powers of Attorney and Living Wills – Some Questions and Answers
- The Capacity Assessment Office
- Powers and Duties of a Guardian of Property

Copies of these can be obtained by calling the OPGT at 416-314-2800. Any group interested in an outreach session is welcome to contact us at the same number.

The OPGT website also has useful information at: www.attorneygeneral.jus.gov.on.ca/english/family/pgt/

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1 S.O. 1992, c. 30.
2 S.O. 1992, c. 2, Sched. A.
3 Ibid.
4 Supra, note 1.

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PSYCHIATRIC PATIENTS AND THE RIGHT OF COMPLAINT

Clare Lewis, Q.C.*

Individuals with serious mental illness are among the most vulnerable in our society. Their rights and dignity while receiving medical treatment should be sedulously fostered.

The Ombudsman is an officer of the Legislative Assembly with very broad powers of investigation. The Ombudsman may recommend corrective measures be taken to address maladministration and may report investigative results to the Legislative Assembly. Under s. 16(2)(c) of the Ombudsman Act, patients in Provincial Psychiatric Hospitals are entitled to have complaints addressed to the Ombudsman forwarded immediately and unopened to the Ombudsman. Since its inception in 1975, the Office of the Ombudsman of Ontario has provided independent complaint resolution
services to patients in Provincial Psychiatric Hospitals, and has been able to resolve complaints from these patients and address systemic issues affecting them, through both informal review and formal investigation.

As part of its mental health reform strategy, the Ontario government began divesting control of a number of Provincial Psychiatric Hospitals in 1998. Six of Ontario's ten Provincial Psychiatric Hospitals have been divested to date and others are slated for divestment. The facilities have been divested to hospitals that, because of their governance structure, are not subject to the Ombudsman's jurisdiction. In the Ombudsman’s Annual Report for 1997-1998, the Ombudsman raised concerns regarding the Province's restructuring plans, noting they would result in patients of these institutions losing their right to complain to the Ombudsman. At that time, it was recommended that the government restore the right of complaint and independent investigation that some had lost and extend this right to others.

It has been the practice of the Ombudsman's office to provide Provincial Psychiatric Hospitals with blank form letters addressed to the Ombudsman to assist patients in making complaints. When the Centre for Addiction and Mental Health was created in 1998 through the merger of the Clarke Institute of Psychiatry, the Addiction Research Foundation, the Queen Street Mental Health Centre, and the Donwood Institute, it became an organization outside the Ombudsman’s jurisdiction. This circumstance caused confusion for some psychiatric patients at the Queen Street site, who continued to send the Ombudsman complaints using the Ombudsman's standard forms. Understandably, it was not apparent to patients how they could be in the same facility, receive the same treatment, and no longer be able to complain to the Ombudsman.

During the fiscal year 2000-2001, the Ombudsman’s office received 130 complaints about Provincial Psychiatric Hospitals, relating to such matters as staff conduct and hospital programs and practices. Between 2000 and 2001, five Provincial Psychiatric Hospitals were divested from the province. During the 2001-2002 fiscal year, as patient access to the Ombudsman declined, the Ombudsman received 63 complaints regarding Provincial Psychiatric Hospitals.

The Ombudsman was involved in consultations with the Ministry of Health and Long-Term Care regarding the proposed Patients’ Charter of Rights and Responsibilities. At that time, the Ombudsman encouraged the development of internal complaint resolution mechanisms in the health system to resolve complaints, at first instance, as well as recourse to an independent investigative body, as a last resort, to resolve outstanding complaints.

Recently, the Ombudsman wrote to the Minister of Health and Long-Term Care in relation to the proposed divestment of the Whitby Mental Health Centre. The Ombudsman expressed general concern that patients in divested Provincial Psychiatric Hospitals lose their recourse to an independent complaints resolution mechanism and also noted that patients in psychiatric units of public hospitals have no such recourse. The Ombudsman stated that psychiatric patients should have recourse to an independent investigative body, as a last resort, to resolve outstanding complaints. He noted that independent review of complaints provides an accountability mechanism that fosters public confidence in the fairness of the review process and that accountability ultimately helps to create a more effective and responsive system.

The Psychiatric Patient Advocate Office (PPAO) performs a very important service for patients of current and divested Provincial Psychiatric Hospitals. Given their circumstances, psychiatric patients often have difficulty expressing their concerns. The PPAO can assist in voicing patient complaints and ensure that they are heard, and is often of assistance to the Ombudsman when complaints from psychiatric patients are received. The PPAO is able to work closely with Provincial Psychiatric Hospitals and obtain insight into their practices that is very helpful to the Ombudsman in reviewing complaints. In February 2001, a member of the PPAO received an Ombudsman Award in recognition of outstanding public service in complaints resolution.2 The PPAO is itself an organization over which the Ombudsman has jurisdiction to investigate and has shown cooperation in resolving complaints about its services.

While the PPAO continues to carry out its mandate, through contractual agreement, in divested psychiatric hospitals, the accountability link is becoming more tenuous. The Ministry of Health and Long-Term Care has indicated that receiving hospitals may elect not to use the PPAO’s services after the first year following divestment. If a hospital elects not to continue the services of the PPAO, the hospital must still provide advocacy services, but patients will not be entitled to complain about such services to the Ombudsman.5

The right of complaint empowers those who are often powerless. Psychiatric patients are particularly vulnerable. The Ombudsman encourages the provision of independent advocacy services to psychiatric patients whether they reside in Provincial Psychiatric Hospitals or psychiatric units of Public Hospitals. The Ombudsman also believes that the right of complaint to an independent complaint resolution mechanism should be preserved when Provincial Psychiatric Hospitals are divested and should be extended to similarly situated patients in psychiatric units of Public Hospitals.

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1 R.S.O. 1990, c. O.6
2 Andre Guitard, Patient Advocate, Penetanguishene Mental Health Centre
3 Since divestment, all of the divested hospitals have opted to renew their service contracts with the PPAO.

* Clare Lewis, Q.C. is Ontario's Ombudsman.
As a tribunal of first instance and in most cases, last instance, the impact of the Consent and Capacity Board on the rights' of psychiatric patients is profound.

A knowledgeable, sensitive, objective and well-informed Board can make the difference between adherence and respect for the rights of psychiatric patients or ignorance and disregard for such rights. It is said that as a society we are in favour of rights until their exercise affects us. The Board and lawyers must strive to protect the rights of psychiatric patients no matter how unpleasant or unpopular the consequences may appear to some.

The quintessential right of any psychiatric patient is the right to apply to the Consent and Capacity Board for a review of the particular issue which affects him or her (i.e. involuntary status, treatment incapacity, financial incapacity etc.). Depending on how the tribunal approaches this right can have a tremendous effect on further rights of the psychiatric patient. If the hearing of the Application is scheduled in a timely manner with appropriate notice and conducted in a manner respectful and sensitive to the needs of the parties, patients will be encouraged to apply to the Board. Without a receptive Board, patients will be discouraged, reluctant and unwilling to apply to have their rights reviewed.

Notwithstanding that a Hearing may be scheduled with appropriate notice and conducted in a manner respectful and sensitive to the needs of the parties, the rights of psychiatric patients are also affected by the approach the Board takes to the “due process” or “procedural” rights of patients.

Psychiatric patients have the right to not only a fair and impartial Hearing with respect to whether or not the evidence is of such a nature to justify the issue before the Board, but also the right to have the procedure set out in the legislation strictly enforced and complied with. The Consent and Capacity Board provides the first and in most cases only judicial scrutiny of such rights. The approach of the Board to the procedural rights of psychiatric patients is therefore critical.

To give little or no weight to procedural rights diminishes not only the process but the person. Are the rights of psychiatric patients to due process somehow lessened or diminished by a compromised mental state? To the contrary, such rights should be more strictly enforced and protected. How “just” can it be to detain an individual suffering from mental disorder yet deny or ignore the right of the individual to due process? If this is acceptable, why have legislation setting out due process or a Board to determine whether the process was complied with?

The Consent and Capacity Board through its’ Decisions, interprets and defines the rights granted to psychiatric patients. In most cases this is not only the first but also the final determination. Although Decisions of the Board are appealable to the Superior Court of Justice, there are few appeals. The reasons for this are many, one being that the Court, with few exceptions, has taken the position that in the case of involuntary psychiatric patients, the patient must continue to be detained at the time of the hearing of the Appeal. Given the length of time it takes for an Appeal to be heard, the likelihood of this occurring in most cases is rare. As a result, although there may be an appealable issue with respect to the rights of a psychiatric patient, the Appeal is considered moot and the Decision of the Board remains.

As a tribunal of first and in most cases last instance, the impact of the Consent and Capacity Board on the rights of psychiatric patients cannot be underestimated.

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FINDING THE BALANCE: MENTAL HEALTH TREATMENT AND PATIENTS' RIGHTS FROM A PSYCHIATRIST'S PERSPECTIVE

Lois Hutchinson

Psychiatrists working in inpatient psychiatric units are faced on a daily basis with difficult situations with respect to the care of the seriously mentally ill. These involve issues such as the apprehension and detention of patients in a hospital setting and psychiatric treatment against patient wishes.

Regarding assessment and detention, the Mental Health Act establishes criteria involving thoughts or behaviour related to self-harm, threats of violence or violent acts towards others, as well as serious mental or physical deterioration of the person after an initial 72-hour period of assessment. The individual must continue to meet these criteria in order to be admitted as a psychiatric patient on an involuntary basis. Often, the patient’s behaviour and mental status change, especially if there has been some initial treatment. There may no longer be grounds for further detention, but the individual may not be well enough to manage in the community. Hence, a “revolving door pattern” emerges, with the psychiatrist becoming the subject of criticism by family members, community agencies or the police when current behaviour is seen as problematic but not serious enough to justify ongoing detention.

Psychiatrists often have to speculate on the occurrence of future dangerous behaviour to support ongoing involuntary hospitalization, recognizing that the prediction of dangerousness is very difficult to make even in a forensic setting. This situation becomes more problematic when there is no prior history of dangerous behaviour in newly diagnosed psychiatric patients.

If the patient chooses to make application to the Consent and Capacity Board to challenge his/her involuntary status, the psychiatrist must then participate in a time-consuming adversarial process to keep the patient in hospital. This process occurs in inpatient psychiatric units where there is an existing shortage of psychiatrists providing psychiatric care. Timing of hearings often does not take the psychiatrist’s work schedule into consideration, and remuneration for participation in the process is poor, especially if the issues are complex, requiring considerable preparation time, or the hearing is lengthy. If the psychiatrist proceeds with the hearing, he/she must act as his/her own legal counsel rather than as a witness providing supporting evidence. In many cases, the hearings are adversarial, with the patient’s lawyer pitted against the psychiatrist and technical and procedural issues dominating the hearing, with the overriding reason for the hearing being lost in the process.

In many cases, patients are discharged prematurely rather than being detained for further observation and treatment. There is evidence that some psychiatric units in general hospitals have very few hearings.

The situation with respect to treatment against patient wishes is often more problematic. Assessment of capacity to consent to treatment is often difficult and poorly done. Patients, by virtue of their mental illness, often exhibit fluctuating capacity during their hospital stay, and capacity for treatment may vary depending on the treatment being proposed and the potential harm associated with it. The process involves the provision of information about the treatment and why it is being proposed, the risks and benefits of treatment and the potential outcome if treatment is agreed to or rejected. This information needs to be documented on the clinical record. It is also well established that therapeutic outcome is much improved if patients are given as much choice as circumstances permit. Once a patient has been deemed incapable with respect to psychiatric treatment, consent must be obtained from a substitute decision-maker, who then must make a decision based initially on prior capable wishes of the patient or in the best interests of the patient if prior capable wishes are not known. The presence of prior capable wishes is often difficult to determine if previous hospital or outpatient records provide a paucity of information about previous capacity assessments. Often the presumption of capacity has been assumed or treatment has taken place because the patient has not refused it. The psychiatrist still has the option to treat without consent on an emergency basis, but what constitutes an emergency may be a debatable issue and subject to criticism.

The patient also has the right to challenge the determination of incapacity and apply to the Consent and Capacity Board, in which case no treatment can occur until the outcome of the hearing is known. Inpatient hospitalization is prolonged, which may expose other patients and staff to harm, particularly if that individual is aggressive and violent when ill. In addition, this situation is seen as taxing the resources of the psychiatric unit, who must provide extra staff to monitor that individual closely and ensure the safety of the unit. Again, patients are often prematurely released from hospital, especially if there is a pressure for inpatient psychiatric beds.

Even if the Consent and Capacity Board upholds the finding of incapacity to consent to psychiatric treatment, the patient can appeal this decision. Hospitalization is further prolonged and treatment is delayed. In this situation, legal representation is provided to the patient but not to the psychiatrist. To date, neither the Canadian Medical Protective Association nor legal counsel to general hospitals see themselves as having a significant role to play in this process.
Given the difficulties presented here, how can physicians and psychiatrists be comfortable with and more fully participate in the process? The following recommendations should be considered:

- Training programs in psychiatry and continuing medical education activities need to focus on education regarding current mental health law and other relevant legislation.
- Inpatient and outpatient psychiatric programs need to develop standards for documentation of capacity assessment and audit these as part of their quality assurance program.
- Changes should be made to the current Consent and Capacity Board process to include making the proceedings less adversarial, ensuring that psychiatrists are adequately compensated for their work and that psychiatrists have legal representation in complex and difficult cases and in appeal hearings.
- Inpatient psychiatric units should monitor the process of detention and treatment as part of their quality assurance program to ensure that the organization's need for efficiency and cost savings is not achieved at the expense of needed care for the mentally ill.
- The Ministry of Health and Long-Term Care, in its parens patriae role of protecting those who are unable to do so themselves, should appoint an individual or establish an office to act as a watchdog to monitor how well the present process is functioning.

In summary, psychiatrists have the professional responsibility to ensure that seriously ill patients receive care appropriate to their condition. However, the discharge of this responsibility is no longer a matter of professional autonomy but is influenced by sociocultural factors, including changes in mental health and treatment legislation and the patient rights' movement. Psychiatrists must become full participants in the processes that have developed as a result of these factors rather than shirk their responsibilities to meet personal needs or the needs of the organization they work for. Only then can they function as true advocates for the patients they serve.


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** IS AN ADVERSARIAL SYSTEM SUITABLE FOR COMMITTAL AND CAPACITY REVIEWS? **

Richard O'Reilly *

An adversarial system is suitable for resolving disputes when a citizen has a clear objective. Thus, a person accused of a crime or an individual who believes that she has been unfairly dismissed from her job are well served by a tenacious advocate who will argue their case. The use of the adversarial system in these cases is appropriate because each individual has a single overriding interest: avoiding conviction and a jail sentence in the first case and reinstatement in the job or compensation in the second. The advocate puts forward every argument to support the individual's case and counters every argument by the state or employer respectively: parties that have an interest diametrically opposed to that of the individual. In the words of the Law Society of Upper Canada:

The lawyer has a duty to the client to raise fearlessly every issue, advance every argument, and ask every question however distasteful, which the lawyer thinks will help the client's case and to endeavour to obtain for the client the benefit of every remedy available and defence authorized by law. In adversarial proceedings the lawyer's function as advocate is open and necessarily partisan.¹

While the adversarial system is an appropriate tool with which to pursue the primary objective of an accused person or a person who believes that he has been wronged, its use to resolve issues, where an individual has conflicting interests, is conceptually flawed. This is the situation when the Consent and Capacity Board (CCB) or courts adjudicate the appropriateness of civil commitment or review a finding that a person is incapable of refusing psychiatric treatment.

Civil commitment is a procedure that involves a balance between an individual's right to liberty and the right to be protected from harm. Society invokes its parens patriae powers to prevent an individual from harming herself intentionally or through neglect. Society also permits civil commitment to prevent harm occurring to others through
the use of its police powers. Commitment to prevent harm to others is usually viewed as being in society's interest and not necessarily in the interest of the mentally ill individual. However, it is not in the interest of an individual with a mental illness to harm another person as a consequence of mental symptoms. Such an individual will usually lose their liberty either in prison as a result of criminal conviction or in a psychiatric facility if found not to be criminally responsible. Moreover, individuals who act violently because of untreated mental illness often experience guilt when their illness remits, following treatment. This is particularly so when, as is so often the case, their victim is a family member.

The second typical scenario that is adjudicated by the CCB and courts is whether an individual with a mental illness, who has been involuntarily hospitalized, can be treated over his objection. In these situations society attempts to strike a balance between the right to privacy and autonomy and the right to treatment and health. We must also recognize that, in this situation, the individual has a right to liberty that is dependent on timely treatment. An appropriately committed patient who is not treated will languish in hospital until he or she dies or has a spontaneous remission, whichever comes first.

Not only is application of the adversarial model to mental health disputes conceptually flawed, its current use has many practical deficiencies, not least of which is the lack of a steadfast advocate for treatment and hospitalization. Traditionally, physicians and, in a more general sense, hospitals have been viewed as the advocates for committal and treatment. However, physicians (and hospitals) are not advocates for hospitalization and treatment in the same way that a patient's lawyer is an advocate for the patient's liberty, autonomy and privacy rights. Physicians are not the equivalent of the Law Society's fearless advocate, advancing every argument for commitment even in instances where commitment is clearly not warranted. Physicians will not act as fearless advocates as described by the Law Society of Upper Canada, advancing every argument for commitment even in instances where commitment is clearly not warranted. Indeed, we would not want them to. Rather, the physician usually takes into account a patient's liberty, autonomy and privacy rights in addition to the right to protection and treatment.

It is not simply an inability to focus exclusively on an individual's health needs that prevents physicians from acting as assertive advocates for hospitalization and treatment. An additional barrier is the altered role that physicians play in the modern mental health care system. The risks facing people with mental illness in the 21st century are substantially different from those they faced through most of the 20th century. Deinstitutionalization has brought about a massive reduction in the availability of psychiatric beds. This in turn has forced physicians to act as gatekeepers, rationing a scarce resource. The role of gatekeeper is incompatible with the role of advocate for hospitalization and treatment.

Nowadays, a Canadian who meets civil commitment criteria and who would benefit from inpatient treatment will often not be admitted. The corollary is also true: many patients are now discharged before they have been adequately treated and sometimes while they still meet committal criteria. We know that many individuals who apply to the CCB for a review of a physician's decision to commit are immediately reassessed by their physician, found to no longer meet committal criteria, and allowed to leave the hospital. In one hospital the number was over 90%. Who advocates for the hospitalization and treatment needs of such individuals in our overcrowded hospital wards and emergency rooms? Family or friends may informally undertake this role but only if these individuals exist, are available, and are capable of the task. What is clear is that physicians and hospitals, which must restrict access to services, often fail to advocate for the treatment and hospitalization needs of individual patients.

I have previously outlined several other problems arising from the use of the adversarial process in mental health elsewhere. Adversarial process leads to an unhelpful fixation on technicalities, often to the neglect of substantive issues. Furthermore, application of strict adversarial process often negates the clinical requirement of providing timely treatment. Our study conducted in two Ontario hospitals found an average delay of 25 days in initiating treatment when patients applied to the CCB for a review of a finding of treatment incapacity. In the same study we reported that patients were detained in hospital, untreated, for an average of 253 days when they appealed the Board's confirmation of incapacity to the courts. These delays may be unremarkable in the context of legal decision-making but are totally inappropriate when applied to clinical treatment.

Other areas of law have embraced alternative dispute resolution processes that are non-adversarial. Examples include changes introduced in recent years in family law. Review of decisions concerning civil commitment and treatment capacity would be better achieved by employing an enquiry-based process, where the tribunal itself is mandated to gather evidence. An enquiry-based process places greater emphasis on the clarifying substantive issues than on strict adherence to procedure. This would allow arbitrators to limit the time spent examining technical errors on certificates of involuntary admission. The futility of focusing on technical errors in the completion of these certificates has been discussed elsewhere. In an enquiry-based process a patient would not have a right to remain silent and thus could be interviewed by members of the CCB during the hearing whether or not he or she elected to give evidence. Alternatively, as occurs in the Mental Health Review Tribunals in England and Wales, the psychiatrist member of the panel could actually interview the patient in private.
and provide the Tribunal with an independent second opinion. The Mental Health Review Tribunals have been criticized for this practice because of the departure from standard adversarial process. Interestingly, critics fail to take into account the substantial evidence showing that judicial hearings (which are classically adversarial) are much less likely than clinical or administrative hearings (which are usually enquiry-based) to overturn a physician’s finding of treatment incapacity.

In conclusion, the process currently in place to adjudicate disputes over civil commitment and treatment capacity uses an adversarial approach that has been borrowed from other areas of law and is inappropriate for resolving issues where an individual has conflicting interests. An enquiry-based process focuses attention on substantive issues and there is a body of evidence showing that it is actually more likely than an adversarial system to result in a decision contrary to, or modifying that of, the treating physician. As physicians are forced into the role of gatekeepers in a resource-limited system, they increasingly fail to advocate for hospitalization or treatment for individual patients. This has produced a distinctly lopsided adversarial system. Therefore, if Ontario elects to maintain an adversarial system, the province must identify and fund an alternative “treatment advocate.”

Abstract

Historically, health care resources were generally perceived as infinite and, to be certain, there was much complacency and abuse of the health care system. Awakening now to the harsh reality of very limited resources and the demand for fiscal accountability, we must reconsider and re-prioritize the various elements in the health care process. However, it is crucial to remind ourselves that, as health care professionals, we are obligated to honour the ethical duties of respect for autonomy, non-maleficence, beneficence and distributive justice. Financial consideration, though legitimate in most instances, must be tempered by the inalienable duty to ensure that no harms befall patients, that the integrity of patient care and treatment is not compromised, and that access to health care is timely and in accordance with justice and fairness.

“A clinician should not dispose of his services under terms or conditions that tend to interfere with or impair the free and complete exercise of his medical judgement and skill or tend to cause a deterioration of the quality of medical care.” (Section 6, American Medical Association Principles of Medical Ethics, 1957)

This paper is primarily concerned with the clinician’s advocacy role and fiduciary relationship with her patients. The law and ethics require the clinician to be the fiduciary of her patients. A fiduciary is defined as “a person holding the character of a trustee, with respect to the confidence and trust involved in it, and the scrupulous good faith and candour that it requires.” It is also a “person having the duty, created by his undertaking, to act primarily for another’s benefit in matters connected with such undertaking.”

Medical ethics, even before the time of Hippocrates, has recognized the unique relationship that the clinician has with her patients. This is largely based on the special vulnerability of patients and the tremendous imbalance of power that exists in the relationship. It emphasizes that clinicians are morally committed to be loyal to their patients, act in their patients’ best interests, to make their patients’ welfare their first consideration (even when their own financial well-being is opposed), and to keep patient information confidential.

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1 Law Society of Upper Canada, Rules of Professional Conduct, 4.01(1).
2 Personal Communication with Michael Bay, then Chair of the Ontario Consent and Capacity Board, September 4, 2002.
5 Courts of Justice Act, R.S.O. 1990, c. C. 43, s. 21.15.

Steve Abdool

THE “BUSINESS” OF HEALTH CARE: ENSURING THAT FISCAL RESPONSIBILITY DOES NOT DETERIORATE INTO SOCIAL INJUSTICE

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THE PSYCHIATRIC PATIENT ADVOCATE OFFICE
Any health care system, therefore, which stands to violate this inherent covenant of trust inevitably works against sound ethical and clinical practice, and ought to be rejected outright. Health care delivery is undeniably a social institution, and medical practitioners must necessarily concern themselves with justice and fairness, especially as these relate to the larger social issues of class structure, poverty, and access to adequate health care.

In this paper, I contend that should clinicians succumb to the current shifting paradigms in the health care system, under the guise of fiscal responsibility and efficiency, they would expose their patients, themselves, their profession, and society in general, to the vulnerabilities and shortcomings inherent in a corrupt, unjust and unfair health care system.

Traditionally, clinicians assumed direct responsibility for managing the care of their patients. In collaboration with their patients, clinicians would decide what diagnostic and therapeutic procedures were indicated, and a third-party payer, for example, the government, would cover the cost. Sadly, there was often little regard for responsible and prudent use of resources, and there is now a legitimate impetus to reform the health care system to ensure efficiency.

The deliberation, however, should necessarily include serious concerns about equity, just distribution of goods and services, and commitments to one another in society. Unfortunately, it is perceptible that shifting trends in our health care system in Canada carry a new model of health care delivery, one of managed care, and the financial incentives inherent in this model seem to run contrary to the advocacy and fiduciary nature of the clinician-patient relationship, as well as to the concept of justice and fairness which we have held very dearly.

In managed-care situations, economic constraints and incentives will control the behaviour of clinicians, and few clinicians will be able to escape from powerful external controls that significantly impact the doctor-patient relationship. Implementing a capitated reimbursement plan would mean that under-treatment, rather than over-treatment or, more significantly, reasonable treatment, would be rewarded. This translates into a deterioration of good quality health care services to the ill, vulnerable and defenceless, and certainly to an increase in the thrust towards a multi-tiered health care system and its inherent injustices.

Managed-care plans can undermine the very foundation of the therapeutic relationship, that is, the clinicians' commitments to beneficence (the moral principle to actively pursue, protect and promote the interest, welfare and well-being of the patient), and non-maleficence (the principle to not cause any harms or evils to the patient). In other words, not only would quality of care be sacrificed through less than adequate care and treatments, but also most likely harms or evils would be caused to patients, current and future.

Managed-care organizations are shrewd enough to allow clinicians to maintain some "control" over the clinical environment. In this way, economic incentives and other coercive influences prod along clinicians, and the managed-care organizations would reap the financial benefits. The primary losers are undoubtedly the patients. They are denied investigations, treatments, and even information that would normally serve to ensure informed choices. This can be viewed as a new medical paternalism.

Paternalism, of course, involves overriding patients' wishes and desires; something which is perceived as unacceptable in the care of mentally competent adults. In managed-care systems, clinicians make most, if not all, important choices for the patient, and the patients don't even know that they are being denied relevant information. Generally, when patients sign up with a managed-care organization, they are not informed about the fact that clinicians are operating under economic incentives to provide less care. Under most managed care systems, clinicians are bound by "gag agreements" to limit how much information and the kinds of information they give to their patients.

On the other hand, clinicians' integrity is also being eroded. It is important that clinicians recognize that they too are being manipulated, and they ought to remind themselves that their allegiance is to their patients and certainly not to the shareholders of managed-care organizations. There is a great deal at stake. After all, health care itself is much more than a mere commodity. It is a personal healing activity that incorporates institutions that embody values such as respect for persons, the value of human life, and duties to care for individuals who suffer.

With a managed-care type system of health delivery, it seems inevitable that clinicians would be caught in conflict of interest situations; for instance, in honouring their fiduciary obligations to their patients and their commitment to third-party insurance organizations. Constraints are placed to control clinicians from ordering "unnecessary" tests and treatments, and, of course, this benefits the patient. However, actions to curb this practice are only desirable when they are in the patient's best interest, not because they serve to profit an organization or a clinician through incentives.

A matter of paramount importance to consider is that clinicians, and not health insurance companies, continue to be held liable when serious problems of negligence arise in the care and treatment of patients. This is the case despite the fact that insurance organizations dictate the constraints to most investigations and modes of care. Clinicians are, therefore, caught in the often competing interest of pursuing patients' welfare and complying with the dictum of health insurance organizations. There are severe consequences to non-compliance, and clinicians
are left in a catch-22 situation – they are coerced to practice less than optimal medicine, for which they are held accountable.

The primary motivation, therefore, for more responsible and fiscally accountable patient care should be honouring the advocacy and fiduciary duties and obligations inherent in the relationship, and not profitability. There is perhaps nothing intrinsically wrong with profitability, however, every health care system must be constructed so as to avert any conflict of interest situation whereby the timely delivery of a high standard of care could be trumped by fiscal consideration.

It is crucial to remember that there exist very few safeguards to protect patients in managed-care plans. It is not difficult to appreciate why quality and safety would not readily yield to the powerful market forces inherent in the managed-care industry. Some argue that the purpose of restructuring is to simply widen the profit margin rather than to improve the quality and safety of care or to be more financially responsible.

We ought to remind ourselves that the cardinal goal of medicine is “serving the community by continually improving health, health care, a quality of life for the individual and the population, health promotion, prevention of illness, and the effective use of resources.” The primary goal of businesses is profitability, and the only governing moral principle for businesses is non-maleficence or not to cause harms, say through deceit, fraud, and so on.

There exists an enormous imbalance of power in the patient-clinician relationship. In a state of vulnerability and inequality, the patient is forced to trust his caregiver. The patient has to reveal his vulnerability and inequality, the patient is forced to patient-clinician relationship. In a state of distress, pain, fear, and apprehension, patients are generally ill-prepared to evaluate the practices and standards of care offered by anyone, especially given the imbalance of power in the clinician-patient relationship. Indeed, this is one of the main reasons for fostering an unblemished trusting bond between the clinician and patient in their fiduciary relationship. The expectation is that one’s clinician possesses the knowledge, skills, and integrity to actively promote and protect one’s best interests and well-being.

A much cherished right in our free society, and one that we frequently criticize other nations for lacking, is that of autonomy or the freedom to self-determine and to choose between options. Should we allow a system such as managed care to infiltrate our health and social structures, we would unwittingly restrict this right to liberty and freedom. The ill, vulnerable, and defenceless among us, increasingly stranded from the fiduciary attention of their clinicians, would become severely limited (even as “consumers in a “free market”) if their choices were narrowed by powerful organizations which provided only specific care and treatment options. This is hardly the same foundation that our liberal democratic society is supposedly built on.

Clearly, it is not befitting for members of the “caring” profession to participate in the repression and bondage of the sick and vulnerable, current and future. After all, in an obviously very symbolic gesture, the father of modern psychiatry, Philippe Pinel, removed the chains from one of the most feared, insane persons at the Bicêtre, a male asylum in Paris, in 1798. The roots of psychiatric practice seem to lie in the liberation of man from control and oppression.

To conclude, medicine is, at its very core, a moral enterprise grounded in a covenant of trust. Today, this covenant of trust is significantly threatened, especially by for-profit forces that press the clinician into the role of commercial agent to enhance the profitability of large insurance organizations. Such minimization and, indeed, distortions of the clinician’s responsibility, often serve to degrade the clinician-patient relationship. Only by unrestricted and unhindered caring and advocating for the patient can the integrity of the medical profession be affirmed.

Remember that elements of a just health care system include universal access, access to an “adequate level” of care, access without excessive burdens, fair distribution of the financial costs of ensuring universal access to an adequate level of health care, and the capacity for improvement toward a more just system. Clinicians should maintain the liberty and independence of clinical and moral judgements. That is, they should not allow themselves to be biased or prejudiced by considerations and interests which will negatively impact upon the care and treatments believed to be in patients’ best interests. Managed-care systems offer much less than Canadian values promise. Clinicians have the right, and indeed the duty, to respond as effectively as possible to unfair attacks on their profession.
Arguably, disparities in the levels of care on the basis of ability to pay are perhaps inherent in a capitalistic society. But clinicians have an obligation to actively work to minimize these as much as possible, and to ensure that patients receive prompt and adequate care with full respect for their human worth and dignity. The public must be re-educated about the true nature of the motivation and function of new models of health care delivery, especially when these threaten societal values.

Clinicians must critically re-examine their role in its historical context, their privileged and powerful position in society, and their covenant with the sick, defenceless and vulnerable. They have been accorded a mighty and noble trust to honour, and they should continue to uphold this with pride and dignity. The alternative is that clinicians might ignore or marginalize their fiduciary role with their patients, and thereby bring about harms and evils to their patients, as well as sacrifice personal and professional integrity, social justice and fairness.

10 Please see, for example: Spragins E. Beware your HMO. Newsweek, 23 October 1995.
11 Nurses’ and other health-related associations and trade unions have been especially vocal in this regard. See, for example: Moore JD, Jr. Labour looks to lead counter-revolution. Modern Healthcare 1995.

CORONERS’ INQUESTS AS A VEHICLE FOR SOCIAL CHANGE

Steven M. Boorne *

Coroners’ inquests play an important role in society by shining a spotlight on the death of those who are traditionally marginalized members of our community. In this regard, they are an important vehicle for social change.

Coroners’ inquests serve a dual purpose by investigating the circumstances surrounding certain deaths, and by making recommendations aimed at preventing other deaths in similar situations. While the investigative function is very important, in most cases it is a relatively straightforward fact-finding process. It is the preventative function that tends to be the most contentious because this is where the jury may make recommendations about matters that are usually broader than the specific events of the death in question. It is also the one that offers the most opportunity to effect social change and to ensure that the death of one of the members of our community will not have been in vain. This is extremely valuable in situations where the death is that of a person who suffered from a mental illness, and the illness relates to the death, either directly or indirectly.

In Ontario, when someone dies in certain public institutions, there is a requirement that the death be reported immediately to a Coroner, who must conduct an investigation. After examining the circumstances surrounding the death, the Coroner may then choose to call an inquest, but is required at law to do so only if he or she forms the opinion that one should be held. Inquests are mandatory in a limited number of situations, for example, when the individual died while in the custody of a public authority such as the police.

In either of these cases, it may very well be that the investigation of the death will reveal systemic...
shortcomings, and often an examination of these, with a view to minimizing their risk of recurrence, will end up being the primary focus of the inquest. The Coroners Act also provides that the Coroner may choose to call an inquest into a death that does not arise from interaction with a public authority or institution, if, in the Coroner’s view, holding an inquest would serve the public interest.

When an inquest is called, the Coroner will empanel a jury of five members of the local community where the death occurred, and parties who may have a stake in the outcome of the inquest will be invited to apply for standing. This includes public interest groups who may have a particular expertise in one or all of the areas which will be examined, or who may have some different perspective to add to the process. Public interest intervenors have been granted standing at a number of recent inquests examining the deaths of individuals who suffered from mental illness.

The Coroner’s counsel, who is traditionally a Crown prosecutor, will present a case to the jury about the facts surrounding the death, and usually some evidence about what could be done differently in the future to prevent deaths in similar circumstances. The Coroners Act contains provisions entitling the family of the deceased, institutions, and public interest groups to obtain standing, cross-examine witnesses and lead their own evidence. These provisions facilitate state accountability and test the government’s view of the death and what ought to be done in response to it.

The jury is then tasked with answering a series of five questions set out in the Coroners Act to explain who the deceased was, and where, when, how and by what means the deceased came to his or her death.

Under the Coroners Act, the jury cannot make any finding of legal responsibility, but it does have the authority to make recommendations to prevent deaths in similar circumstances. This, in my view, is where families and public interest groups have a powerful role to play in effecting systemic change. I believe that if a recommendation can reasonably be said to be directed to the avoidance of death in similar circumstances, or if it is based upon evidence of any other matter arising out of the inquest, it should be allowed to be put to the jury for their consideration. The case law is clear that it is up to the jury, and not the Coroner, to perform the fact-finding function and to make recommendations.

For example, when the Psychiatric Patient Advocate Office (PPAO) participated in the inquest into the 1997 death of Cinderella Allalouf, there were several issues which the Coroner and the other parties with standing did not wish to have explored during the inquest. It was our strategy to keep raising these issues with the various witnesses called. Thankfully, for the most part, the jury appears to have agreed with us and made a number of important recommendations aimed at changing, for example, certain practices of the hospitals with respect to the use of locked seclusion, as well as imposing additional notification requirements on hospitals in their dealings with the Ontario Review Board.

Another important aspect of coroners’ inquests is that I believe they have a deterrent effect on public institutions. At the most basic level, inquests garner a lot of publicity and force institutional interests to pay attention and often to respond in a proactive manner. In my experience as counsel at inquests, public institutions take inquests very seriously, as negative findings can have a detrimental effect on their public image and the reputation of those involved. When a death occurs, it is in their interest to investigate and, if mistakes were made, to correct them prior to the inquest. This allows them to send a message to the jury and the community that they take the death seriously and are willing to learn lessons from it. It also allows them to play a role in crafting recommendations which are the most reasonable in the circumstances.

While some may say this is very self-serving, the fact is that a recommendation that is reasonable and practical, especially if it is endorsed by the public institution that will have to put it into action, has the greatest chance of successful implementation.

Inquests also require public authorities to account to the Office of the Chief Coroner about what recommendations have been implemented and if not, why not. This is an important mechanism which is built into the system to ensure that once the spotlight of publicity from the inquest fades, the recommendations will not simply be shelved.

Finally, an important new development in this area is to seek a jury recommendation calling on the parties who have had recommendations directed to them to report back to the jury and to the community about the status of those recommendations in one year’s time. This helps maintain some public scrutiny of the actions of these institutional actors, and to create a record in the event of a similar situation occurring in the future. If it does and there has been a failure by public authorities to act on previous recommendations, this may have important civil liability implications.
MANDATORY INQUESTS: A CASE FOR EQUALITY

Robert Illingworth *

My brother’s death as an involuntary psychiatric patient in Ontario brought me face to face with the Ontario Coroners Act. Reading Section 10(4) of the Act dealing with mandatory inquests evoked both anger and disillusionment. The exclusion of involuntary patients from the umbrella of custody and detention is discriminatory and violates their Charter rights. By not providing a mandatory inquest for these patients, the omission can limit the affected family’s opportunities to gain a full understanding of the circumstances of the death.

The following is my personal experience with the Coroner’s system in Ontario.

Background

My brother was diagnosed as bipolar. In 1995, he was admitted to a psychiatric facility in Ontario as a voluntary patient. The morning after his admission, he was permitted to go for an unsupervised walk. He did not return. In his absence, his status was changed to that of an involuntary patient. He was returned to the facility by the police and his custody was turned over to the facility. At no time during his detention in the hospital did he see a Rights Adviser to inform him of his right to a review of his status. Other elements of his stay involved psychiatric drugs, a physical confrontation when he attempted to leave, chemical and physical restraints, and in the end, death in restraints (cause of death undetermined).

Grieving a death is a difficult process. This process is compounded when the death is sudden, unexpected, and involves a vulnerable member of society. The death of my brother was a death to many – the loss of a son, a father, a grandfather, a brother, an uncle, and a friend. The family seeks answers to assist in understanding the circumstances of the death and to arrive at closure.

Death investigation in Ontario is the mandate of the Ontario Coroner. The investigation attempts to answer the who, when, where, and how, and to clarify the circumstances of the death. The motto of the Ontario Coroner is: “We speak for the dead to protect the living.” The voice of the Coroner can be heard through the available investigative tools. In the case of a custodial death, the loudest voice resounds in the Coroner’s Court. The inquest provides the opportunity to hear from those who interacted with the deceased up to the time of death. Unfortunately, those who die while detained in the “custody” of a psychiatric facility are not considered custodial under section 10(4) of the Coroners Act,1 and therefore, are not entitled to a mandatory inquest.

My Perspective

As the brother of the deceased, I was left with the unexplained death of a patient involuntarily detained in the custody of a psychiatric facility. My family and I were left with many unanswered questions, an undetermined cause of death, and no entitlement to a mandatory inquest. The frustration rose with the realization that a prisoner or alleged criminal in the custody of a peace officer is provided with a mandatory inquest because his/her custody is “Custody” with a capital “C.”

I always believed that “deprivation of freedom” is “deprivation of freedom.”

In the case of R. v. Weber,2 Justice O’Connor cited a decision of the Consent and Capacity Board in the case of Re KS3 as follows: “The Mental Health Act is replete with procedural safeguards. The safeguards have been implemented in recognition of the fact that a patient detained under the authority of the Mental Health Act . . . has been deprived of their liberty, autonomy or right of self-determination no less than an individual who has been imprisoned.”

It is my contention that section 10(4) of the Coroners Act is discriminatory when examined against section 15(1) of the Canadian Charter of Rights and Freedoms,4 which provides for, in part, equal benefit of the law without discrimination due to, mental or physical disability. This belief, in conjunction with a perusal of the Ontario Human Rights Code,5 resulted in a submission to the Ontario Human Rights Commission.

My submission led to a letter from Keith C. Norton, Chief Commissioner of the Ontario Human Rights Commission, to the Chief Coroner of Ontario. In reference to section 10(4) of the Coroners Act, and the discretion of the Coroner to decide whether the circumstances merit an

advise in many other psychiatric facilities. It also has a legislative duty to provide rights advice training.

Ms. Allalouf, who was the subject of an order of the Ontario Review Board that she be detained in a psychiatric hospital,

"Steven M. Boorne of the Ontario Bar. The writer wishes to acknowledge the assistance provided by his colleague Richard Macklin in discussing some of the issues raised in this paper, and for his helpful comments on an earlier draft.

1 10 Ms. Allalouf, who was the subject of an order of the Ontario Review Board that she be detained in a psychiatric hospital, became pregnant while a patient in an all-male unit at a psychiatric facility in Toronto and died of complications arising out of childbirth.

2 1 R. v. Weber,

3 2 Justice O’Connor cited a decision of the Consent and Capacity Board in the case of Re KS as follows: “The Mental Health Act is replete with procedural safeguards. The safeguards have been implemented in recognition of the fact that a patient detained under the authority of the Mental Health Act . . . has been deprived of their liberty, autonomy or right of self-determination no less than an individual who has been imprisoned.”

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5 4 My submission led to a letter from Keith C. Norton, Chief Commissioner of the Ontario Human Rights Commission, to the Chief Coroner of Ontario. In reference to section 10(4) of the Coroners Act, and the discretion of the Coroner to decide whether the circumstances merit an
inquest, Mr. Norton states: “This appears to provide for a different level of protection for persons who are in custody due to mental illness and may be vulnerable to challenge as being discriminatory.” Mr. Norton goes on to say: “The deprivation of liberty is no less severe than while in the custody of a peace officer or correctional institution. Indeed, involuntary patients may experience greater restriction on their liberty and autonomy as they may be subjected to physical, mechanical and chemical restraints.”

Conclusion

In reference to the death of an inmate at the Sudbury Jail, Dr. Elmer Uzans, Regional Coroner for Northeastern Ontario was quoted as stating: “When you have someone in custody, it means there is someone else in control.”

Where else is an individual under the same degree of control by others as when he/she suffers from a mental disorder and is detained involuntarily – under the influence of powerful psychiatric drugs; at times, physically and chemically restrained, and often not oriented to his/her physical surroundings.

Death while in custody as an involuntary patient deserves the loudest voice of the coroner. The family must be satisfied that they have been provided with every opportunity to pose questions to those most involved with the patient at the time of death.

When the Coroner is investigating a death in prison, he/she is scrutinizing professionals in a field of endeavor separate from his/her own. In the case of the involuntary patient, the Coroner is put in the position of scrutinizing members of his/her own profession. This leaves the door open for the possible public perception that he/she is reluctant to call discretionary inquests. The family of a deceased denied an inquest may perceive that the death of the loved one is less worthy or important because of the mental illness.

My family’s experience with the Coronial system has led us to conclude that the section of the Act dealing with mandatory inquests for deaths in custody is inconsistent with the Ontario Human Rights Code and the Canadian Charter of Rights and Freedoms. It is incumbent on the present government to amend the Act to eliminate the inconsistencies and in the recommendations of Keith C. Norton, in his role as Chief Commissioner: “It would, therefore, be preferable for coroners to hold inquests in all cases where a patient dies while involuntarily held in a psychiatric facility in Ontario.”

3 Dated March 6, 1991.
7 K.D. Plouffe, Northern Life, lifepage, April 5, 1996.
8 Supra, note 4.
9 Supra, note 3.

* Robert Illingworth is a member of the public with a specific interest in rights and equality issues as they pertain to involuntary psychiatric patients.

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CONSUMER/SURVIVOR MOVEMENT IN PROMOTING PATIENTS’ RIGHTS IN ONTARIO, 1977 TO PRESENT

Geoffrey Reaume *

From the Ontario Mental Patients Association to the Ontario Psychiatric Survivors’ Alliance to People Against Coercive Treatment, the history of groups promoting patients’ rights, organized by consumers, survivors, or ex-patients (“c/s/x” for short) has a vibrant history in Ontario over the last quarter century. As diverse as the people they represent, these various organizations have ranged from anti-psychiatry to pro-psychiatry to groups that fall somewhere in between.

These groups began during a period of widespread activism among people demanding greater inclusion and rights in society – Native people, Blacks, gays, lesbians, women, prisoners, and others. These wider developments throughout North America and elsewhere in the world influenced the earliest activists in the c/s/x movement, as groups began to be set up by ex-patients in different parts of the United States and western Canada in the early 1970s. The Mental Patients Association in Vancouver, which began in 1970, was the first group of its kind in Canada. In Toronto there were several short-lived groups during the mid-1970s. However, it was the Ontario Mental Patients Association, founded in 1977 (called On Our Own from 1980) which was the first long-term established organization in central Canada.

Several newsletters and magazines came into existence as well around this time. The Cuckoo’s Nest lasted from 1979 to the mid-1980s and was written by ex-patients, including editor Pat Capponi, who later wrote several well-known books. It focused on conditions in boarding
homes in Parkdale, just west of Toronto's Queen Street Mental Health Centre, during the early days of widespread deinstitutionalization. This publication helped to bring more attention to the poverty experienced by discharged patients from the perspectives of people who lived it. *Phoenix Rising* was published in Toronto from 1980 to 1990 and became Canada's most well-known anti-psychiatry magazine. It was founded by Don Weitz and Carla McKague, both of whom had been in mental institutions. Among other things, this publication helped to disseminate legal information and news about patients' rights during this period and was the only national magazine of its kind in Canada. Both publications, and others that came along afterwards, such as the *Consumer/Survivor Information Resource Centre Bulletin*, published in Toronto since 1992, have been important in raising awareness about c/s/x advocacy in the community, as was discussed or advertised within their pages.

Making links with other like-minded groups has helped to promote patients' rights in the province. While links with cross-disability organizations have often been elusive, history shows the benefit of such collaboration for all people defined as disabled. One of the earliest example of c/s/x and disability rights activists fighting a common cause was through the Coalition on Human Rights for the Handicapped. This group was founded in early 1980 to fight against the exclusion of people labeled handicapped from the new Ontario Human Rights Code, specifically those who were not covered in the anti-discriminatory provisions of this law. Activists from On Our Own joined forces with various other groups, including the Blind Organization of Ontario with Self-Help Tactics (BOOST), Canadian National Institute for the Blind, March of Dimes, Advocacy Resource Centre for the Handicapped, Canadian Mental Health Association Ontario, and the Ontario Association for the Mentally Retarded. Their definition of handicap included people undergoing psychiatric treatment, a position which the Ontario government initially opposed. This broad-based activism eventually pushed the government to agree that mental handicap should be included as coming under anti-discrimination laws, a crucial protection for people in all walks of life.

The creation of legal aid centres in Ontario during the 1970s and 1980s facilitated more widespread involvement of lawyers and legal aid workers, who fought for civil rights of patients with ex-inmate activists. This included holding public forums such as a Patients' Rights symposium which was held at Ontario Institute for Studies in Education in February, 1982. A broad range of legal issues were discussed at events such as this and was attended by lawyers, health care professionals and current and former patients. Some of these legal workers were themselves ex-inmates, such as Carla McKague. She was very involved during the 1980s and early 1990s in rights advocacy for people with a psychiatric history, notably in areas dealing with consent to treatment and arguing against forced electroshock. In the mid-1980s, lawyers with the Advocacy Resource Centre for the Handicapped (ARCH) joined forces with On Our Own to advocate giving people in mental institutions the right to vote in elections. This led to this right being enshrined in law. Psychiatric patients in Ontario were able to vote for the first time in the 1985 provincial and municipal elections. This right was later extended federally in time for the 1988 Canadian election after years of activism and advocacy by people across the country, including in Ontario.

Ex-patient activists have also been involved in the rights of forensic patients. The Ontario Coalition for Humane Treatment of Psychiatric Offenders was founded by Oak Ridge ex-inmate Randy Pritchard in 1988. During the four years of its existence this group advocated for improved living conditions for prisoners and investigation of abuses of patients by staff. Forensic patients have had to contend with prejudice not only from the wider community but also from some ex-patients who do not wish to be identified with people labeled "criminally insane." To promote more solidarity and rights protection of people in the criminal justice system, Prison Justice Day has been held annually on August 10, marking the day in 1974 when Millhaven inmate Eddie Nolan was found slashed to death in solitary confinement.

Solidarity and rights protection was a major platform of the Ontario Psychiatric Survivors’ Alliance. Its heyday was between 1990-1992, during which time 60 groups around the province were founded under its umbrella. However, this growth proved too much to be sustained and the organization eventually folded after a number of internal disputes. OPSA was the first provincial-wide rights advocacy organization run for and by current and former patients. Despite its problems, it provided impetus for other local groups to carry on advocacy issues and offered otherwise socially isolated people a venue in which to connect with others concerned with patients’ rights.

Other groups which developed during the 1990s included groups which provided services to the province’s ethnically diverse population, such as the Chinese and Southeast Asian Consumer/Survivors Self-Help Centre. Groups for women who had been in the mental health system as well as for gays and lesbians also came into existence in Toronto, at places such as Sistering and 519 Church Street Community Centre, which offered peer support to participants. A crucial component of peer support includes giving people information with which to make choices in their lives. This in turn can raise awareness among psychiatric consumers and survivors about their legal rights. From an increased awareness of rights flows a greater desire to demand inclusion in society as a way of asserting those rights. One such manifestation of this has been the Psychiatric Survivor Pride Day, or Mad Pride Day, held in Toronto every year since 1993 (except 1996). Legal rights protection has often been a part of events such as this, in which workshops offered by activists discuss issues ranging from
housing to treatment. Of course, there have been setbacks, as well, which have prevented any claim to “victory” in the overall rights agenda. Community Treatment Orders, which became law in Ontario in 2000, have raised major concerns among psychiatric survivor rights activists. Groups such as People Against Coercive Treatment and the Queen Street Patients Council spoke out against its implementation. It remains one of the most contentious areas in contemporary mental health law.

The need to come up with terms which people do not find discriminatory has been another area of controversy since the earliest days of the c/s/x movement. For example, the term “patient” came to be increasingly rejected by anti-psychiatry activists during the early 1980s. They argued that this term had been used to pathologize people who received psychiatric treatment as being hopelessly sick and therefore not worth listening to. This self-description also included seeing people who had a psychiatric history as not only victims of oppression but also as having survived psychiatric abuses, thus people began to call themselves psychiatric survivors on a widespread basis by the late 1980s. During the same decade, the term “consumers” also gained currency among professionals and patients who supported the medical model. However, there are plenty of people who dislike the term consumer for its marketplace implications, as if people have many choices in selecting medical or legal services, when some might feel this is hardly the case. In order to try to bridge these differences, over the last decade these two terms, “consumer” and “survivor,” often joined as “consumer/survivor,” have become among the more well-known forms of self-identification. More recently, some people have begun to call themselves “survivors” as meaning they have survived mental illness rather than psychiatry. So this language is forever being redefined by people who use it as a form of self-identification. In so doing, these efforts are aimed at combating much of the prejudice that has been around for generations.

Various efforts to promote psychiatric patients’ rights over the last 25 years in Ontario and elsewhere by people who have themselves been in the mental health system have led to a number of improvements, not the least of which is hearing more from people who have supposedly been “voiceless mental patients.” But rights protection is still not as good as it should be. One particularly important area that needs improvement is the coordination of advocacy efforts in the province. Bringing diverse efforts together and funding more psychiatric survivor-led legal aid projects on a provincial-wide basis would help to make the protection of patients’ rights more effective. If recent history has revealed anything, it is that improving legal rights protection for psychiatric patients must involve current and former patients in every step of the legislative and implementation process. Whether these same advocates will actually be listened to is something that only the next 25 years can tell.

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Interview: Randy Pritchard, January 18, 2003


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**WORKING FOR A CHANGE**

Diana Capponi*

January 23, 2001: “In addition, $1 million will go to the Ontario Council of Alternative Businesses to create employment opportunities.”

Elizabeth Witmer – Ontario Minister of Health and Long-Term Care, 2001.

What a day! After ten years of proving to ourselves and others, constant negotiating, constant marketing, explaining ourselves – they finally heard. Real work for real money! Employment is on the agenda; finally, the system seems to understand that medication and a disability cheque are not “success stories.” People, including the consumer/survivor community, need to feel useful, need to have an identity other than “mentally ill.” We need to see a future. The Ministry got it!

Think about it. When have the words “mentally ill” and “employment” ever been heard together? Or “mental health” and “healing”? Usually when a headline reads “mentally ill,” it also reads, “on the street, subway pushers, new drugs, homelessness, fire starters...” Mental illness sells papers. The media loves stories about us – always the bad stories. Very few good ones hit the press.
The public still holds draconian views about us, in part because the media appeals to their fears. We can't blame the public. Until 20 to 25 years ago, those deemed “mentally ill” were locked up with no hope for a future.

Since deinstitutionalization, communities across Ontario have been flooded with discharged “psychiatric patients,” people who walked funny, looked funny and strange, were often unkempt, and incredibly poor. These behaviours were interpreted as mental illness, rather than the long-term effects of institutionalization and poverty. The “system” was not proactive in assisting people to reintegrate into communities, nor did it help in educating people about the realities of mental health/illness. Still today, the emphasis both financially and in terms of service provision is on clinical treatments (medication), crisis response, clubhouses, etc. There are few efforts to address the quality of life most psychiatric survivors experience. Poverty is almost completely ignored; in fact, its affects are often pathologized as yet another psychiatric symptom. Only recently has employment become a significant indicator of “rehabilitation.”

Many types of employment programs have been operating for years. In fact, at one point patients had to work in the institutions because the provinces could not afford, or were unwilling to spend the money, to take care of the asylums. Then, interestingly enough, we had the skills to farm, to do laundry, to clean floors and windows, to sew and to cook, with little supervision or support. Once dollars for supervision and support began to flow, yet another industry was created entitled “vocational services.”

Once these supports became professionalized, we found some pretty horrific approaches to “work,” sheltered workshops among them. Today there is still an 85% rate of unemployment among consumer/survivors in Ontario, and the amount of funding going to vocational services continues to grow.

It became very clear to the survivor community that expectations of our abilities were either absent or non-existent. We heard over and over again that work is stressful, that we should not set ourselves up by trying to have productive lives, that we should focus on getting ODSP and be content with the medication schedule. We have spoken or met with folks who were paid $15 a day (for an eight-hour day), people who were paid with cigarettes. We witnessed people trying to work with little or no supervision or training, and people having jobs, then having to give them up because their turn to have a job expired after six months. It appeared that few job supports or real work was available to our community.

Looking Back

So how did this amazing movement begin? The first thing I remember is the Consumer/Survivor Conference at the Westbury Hotel in Toronto in 1992.

The Consumer Survivor Development initiative had been operating for about a year and had funded about 37 self-help groups. There was no reform process at that time. I was working at Fresh Start, a consumer/survivor cleaning business; A-Way was operating; Cambridge Active Self-Help (CASH) was established; and ABEL Enterprises was running a woodworking shop in Dunnville. There were also a number of Affirmative Businesses interested in becoming independent. But no one had really articulated what these various businesses did and how they did it. We had to figure out who we were and who they (the providers) were. Often the finances were in a muddle in both agency and consumer/survivor-run businesses. There was no sense of what the businesses represented or what they could become and in the general community it wasn’t considered reasonable for “crazies” to work. But people were working and there were huge waiting lists of potential employees for each business. At this conference the notion of an umbrella group or council of consumer/survivor businesses came up.

After that, we really started to hone in on and define what it was that we were doing. We had spokespeople who helped us along: Jacques Tremblay, David Reville, Pat Capponi, and Kathryn Church. We submitted a proposal for the Consumer Survivor Business Council of Ontario and started with a budget of $76,000 from the Ministry of Health. Kim MacNeil from CASH, Mary Taylor from ABEL Enterprises, Keith Hambly from A-Way, and Norma Jean Crawford from Raising Your Self-Esteem, Chatham, and I were the founding members.

It took a while to get incorporated and in the meantime, A-Way flowed the money and provided an office space. There were management problems early on and we had to shut down the office after six months, but the Board members carried on since we kept getting requests for community economic development information. During that time, we managed to publish Group Hallucinations: Overcoming Disbelief – Yes You Can Start a Community Business in partnership with the National Network for Mental Health. When new funding came through in 1993, I left Fresh Start to take on the work of the Council.

I learned about funding and about the need to show very concretely what you can do, to profile our success stories, and use them to inform others. Documentation of work is so important. From Kathryn Church, we started to learn the value of writing for different audiences in order to get the information out and inform as many people as possible about what we were doing. In 1994, we opened Prezents of Mind, a store that sold consumer/survivor handicrafts, and ran it for several months. The funders were blown away by the motivation of the survivor community and the quality of products in the shop.

At an event in June 1996, we moved back into our offices on 761 Queen. There were 500 people in attendance at the re-opening of the community centre. Representatives from the City, the Province and the Federal Government were all there. I realized it was a big deal. A few weeks later the Raging Spoon opened on the first floor of 761.
But there were and continue to be more hurdles to overcome. In 1998, a TV sports announcer in Ottawa was shot by a “crazy.” At about the same time, the Toronto Star ran a series entitled “Madness” that linked mental health issues with violence. The result of this increased public concern over mental illness was that the Province decided to hold a review of its Mental Health Reform process. This was year five of a ten-year process. Dan Newman, Legislative Assistant to the Minister of Health, headed up the review. At a press conference, I invited him to a consultation at the Raging Spoon. With two weeks’ notice, we had 27 deputations from consumer/survivors from around the province. So proudly I watched survivors deliver well-researched and hard evidence and facts that could not be disputed. Such a long way from the Graham Report of 20 years ago… They gave statistics, talked about their work, the mental health care system, and the need for reform. Mr. Newman spent the entire day listening to us. Although Bill 68 was passed, Mr. Newman referred to the Home, a job, and a friend, that most of the 27 deputations spoke to in the new Reform document, Making It Happen.

In 2001, Janet Ecker announced the New Employment Support Program, which did not require people to be labeled as “permanently unemployable” in order to be deemed disabled and also added the Employment Supports Program, which allowed for disabled people to identify their vocational ambitions, and to even shop for their own services. What a concept! Furthermore, the Ministry had developed an Innovative Project Fund, established to support new and innovative approaches to employment, and they used alternative businesses as examples of innovation. The announcement was made from the Raging Spoon. They were using our language – “real work for real wages, and supportive and competitive.” I remember getting goosebumps and thinking that though it takes so long, it pays off.

Did we grow! We even underestimated the power of self-help, the power and dignity of earning a living, the pride in “doing a job well.” We see every day that people will live up to or down to what others expect of them, and we see how often our community is rejected by the mainstream.

We developed a process by which we could control and design businesses that would accommodate the needs of the survivor community, the most important need of being included. Many of us have untapped business sense, many of us have survived through tough circumstances and are still alive and breathing. These are all transferrable skills and the number of survivors honing their various abilities has grown tremendously over the past 12 years. There are now over 57 self-help groups across Ontario, and today there are 11 businesses, with many more on the horizon. As a community, we have obviously benefited tremendously from the pilot work of David Reville, Don Weitz, Pat Capponi, the Consumer Survivor Development Initiative, and OCAB. Initially it was important to be able to come together and meet, to have some safe space in which to be ourselves. Then we moved on to economic justice. We were determined to prove that we could do it not only to others, but to prove it to ourselves as well. With the collective employment created over the past 12 years, our payroll records prove that “We Can and We Are.”

Disappointingly, our worst critics have been those in the Mental Health Care System. Those who make statements such as: “Well, my people don’t want to work, and they can’t.” “My client isn’t ready to work, he doesn’t have any housing.” “We don’t want to set people up.” “This person is extremely anxious and I don’t want him to get too stressed.” “Our membership has had too many changes lately, so we don’t think it would be a good idea for them to see the video [Working Like Crazy].” While most service providers support an individual’s right to work, they firmly believe that their clinical supports are more critical than a person’s dignity, integrity, and financial status.

Businesses love us, industry loves us, and psychiatric survivors love us, one can only wonder why the support services don’t, or are critical or defensive. Frankly, how can anyone defend the system, when we look at what’s happening on the street? When I go downstairs to the Parkdale Area Resource Centre (PARC), I watch the folks coming off the street, no socks, often no jacket, purple and blue heels and noses from the extreme cold, muttering words to themselves or to no one in particular. How I wish we had work to offer all of them.

The Future

There has been a huge shift in expectations in the past ten years. Several businesses are being run by consumer/survivors. There are jobs, people are making business plans, scheduling work, marketing their products. We’ve changed the conversation. Now the Ministry is asking for advice. We have to learn to respond and to get them to use that advice. There is now an expectation that you can be crazy and work. No one cared about work before, just sheltered workshops. Now there are workplaces, schedules, and marketing practices. We’re excited about the recent announcement by Tony Clement of an additional $250 million investment into mental health care in Ontario. We have to stay on guard and monitor how the money is spent. I hope that the bulk of it will go to new and innovative approaches to improving the quality of life for people. I truly hope it will reduce the 85% level of unemployment for survivors.

*Diana Capponi is a psychiatric survivor who was the former Executive Director of Fresh Start Cleaning, and is a founding member and Executive Director of the Ontario Council of Alternative Businesses.
ONTARIO MENTAL HEALTH SYSTEM: ISSUES FROM THE PERSPECTIVE OF A COMMUNITY-BASED PROGRAM SERVING PERSONS WITH MENTAL ILLNESS

John Bowcott

In April of 1990, a group of very timid consumer/survivors, with the encouragement of the Patient Advocate of the North Bay Psychiatric Hospital, made a presentation to the Graham Sub-Committee on Mental Health Reform. This presentation marked the beginning of what is now People for Equal Partnership in Mental Health (PEP), an organization where I am proudly employed and that speaks out on behalf of consumer/survivors with the goal of improving and enhancing their quality of life. PEP also aspires to encourage and empower consumer/survivors to participate in the planning, management, evaluation, and delivery of the mental health services.

Since the Graham Report, the North East has seen considerable expansion in the consumer/survivor movement. Initiatives have been established in most of the major cities of North Eastern Ontario: Sudbury, Timmins, Huntsville, Parry Sound, New Liskeard, Sault St. Marie. These initiatives contribute to the mental health system by facilitating the development of programs for consumer/survivors, run by consumer/survivors. These programs are uniquely geared towards members' needs and are provided in a safe and supportive environment where consumer/survivors need not worry about being judged or labeled.

Consumer/survivor initiatives enable programs to be offered that are vital to the health and well-being of consumers. Peer support programs allow consumer/survivors the individualized interactions that often help reduce their stay in hospitals. Self-help programs assist consumer/survivors in developing the tools they need to be successful in their daily lives. Advocacy and education, geared toward government, professionals and the public, are critical in promoting the growth and development of these initiatives.

The initiatives are membership driven, with a Board of Directors made up of consumer/survivors. The Board of Directors is normally elected by members at the Annual General Meeting. Monthly members meetings encourage the involvement of all members in the initiative’s operations. Most organizations are incorporated with solid organizational structures in place, and operate based on a well-defined mission statement, goals and objectives, detailed by-laws, as well as formal policies and procedures.

Community involvement is essential for the ongoing success of these initiatives. Members, board and staff sit on boards and committees to provide valuable input in the planning and delivery of mental health services and programs in their communities. The exchange of information and knowledge helps community members develop an increased understanding of consumer/survivor initiatives, their goals and challenges, often leading to further community support.

With the help of a grant from the Trillium Foundation, consumer/survivors have organized and established a network called the North East Ontario Consumer/Survivor Network (NEON), made up of consumers from all the regions in the North East, as well as Native, Francophone, and family representation. The network enables the groups to support, encourage, and advocate together on many issues and concerns.

Because of the Trillium grant, many Northeastern initiatives have been able to improve their technology by purchasing computers that enable their members to meet via chat forums and/or to correspond via email. The network also meets on a regular basis, where members can communicate common concerns, help other initiatives which may be experiencing problems, and share ideas about self-help and education programs. Overall, it is a mechanism by which each initiative can grow and develop individually through the collaborative efforts of the network.

There are many ongoing challenges faced by consumer/survivor initiatives. In a recent letter to the Honourable Tony Clement, Ontario Ministry of Health and Long-Term Care, the Ontario Peer Development Initiatives (OPDI) comments:

One issue of concern to all of us is the serious under funding faced by [consumer/survivor] organizations. For most groups, funding has not increased for over ten years, despite the fact that both program costs and the number of people we are involved with and served by our groups have increased dramatically. There are also a number of unfunded initiatives across the province that need a mechanism to access funding if they so desire. We are therefore pleased to read that the Provincial Themes document specifically recognizes the “current lack of funding and formal status for peer support initiatives.

Consumer/survivor organizations have proven to be models of efficiency which have been effective in helping people stay out of hospital, as well as improve their quality of life. Consumer/survivor groups offer peer support and employment that promotes recovery and independence, rather than dependency upon mental illness services. Recently released first year results of the Trillium-funded Connections Program demonstrates that peer support helps people successfully make the transition from institutionalization to community life.
This type of peer support saved the health care system up to $12 million dollars in hospital costs (Cheryl Forchuk, RN, Ph.D.). Despite the demonstrated effectiveness of the alternatives that consumer/survivor and consumer/survivor and family initiatives offer, our current level of funding represents less than 1% of the mental health budget.1

Meaningful employment for consumer/survivors is another major challenge faced by these initiatives. Inequities in funds available for staffing, as compared to larger mental health organizations, including lower salaries and lack of benefit packages, lead to the loss of key staff to these larger organizations. Often consumer/survivors employed by these initiatives are paid significantly less than those employed by other mental health organizations, yet the stresses and level of responsibility are certainly not lessened. Supports in place for staff in terms of benefits are simply not available. Professional development also suffers and burnout is a major concern.

Ensuring that the voice of the consumer/survivor is heard and that their ideas and life experiences are utilized is another major challenge for these organizations. When participating on boards and committees, consumer/survivor contributions are not always fully respected. Sometimes they are a token or a means for an organization to meet a consumer/survivor quota. Board and committee members need to realize the true value of consumer/survivor input, being often based on real life experiences.

Through the continued involvement of consumer/survivors in all aspects of these initiatives, the continued creation of quality programming, the utilization of community involvements, and the establishment of area networks, it is hoped that these major challenges can be overcome.


* John Bowcott is a consumer/survivor and the Program Manager for People For Equal Partnership In Mental Health (PEP), a consumer/survivor initiative in North Bay, Ontario.

STIGMA

Scott Simmie *

John has a diagnosis of schizophrenia. And for him, that label – people’s reaction to that label – has been an albatross. Never mind that he’s happily married, that he’s funny, that he knows hockey inside out. Doesn’t matter. He’s been crazy. Therefore, he is somehow “not one of us.” Not normal. Less than normal. Abnormal.

The word “stigma” is Greek in origin – and its meaning had nothing to do with mental health. It referred to the practice of burning or cutting a mark into the flesh of criminals and slaves. The mark served to make their status apparent to all; a label that would set them permanently apart.

In some ways, we haven’t made much progress. We still brand people. The physical markings may be gone, but an invisible stamp of ‘the other’ is often squarely applied to the forehead of someone with a mental disorder. It remains the most common concern voiced by consumers.

“Stigma,” goes an oft-repeated saying, “is worse than the disorder.”

Unless you’ve been on the receiving end, it’s tough to comprehend how that statement could possibly be true. Surely the disorder is the problem – and once that’s under control everything else is fine, right? Well, in a perfect world that would be the case.

People with mental health problems would be universally regarded as equal members of society. They would be supported by understanding co-workers, landlords, friends, and family. They would be seen for who they are – not what they’ve been diagnosed with.

Unfortunately, the real world doesn’t work that way. While there’s been some progress, having a mental disorder can still throw up roadblocks to friendship, housing, and work.

“You should call stigma what it is,” one woman stated bluntly: “Discrimination.”

The kind of discrimination where a Canadian bank can refuse loan insurance if you’ve ever been diagnosed with a mental disorder. Where private health insurance can be denied if you’ve ever seen a psychiatrist. Discrimination based on fear, misunderstanding and just plain ignorance. A mindset that excludes rather than includes. More than one person has compared it to apartheid.

Such an extreme comparison may not be too far off. Perhaps the starkest example of prejudice we’ve noticed was on the manicured grounds of a major psychiatric hospital in Toronto. Just a few metres from a busy sidewalk was a simple sign. It was supposed to read: “Dogs must be kept on a leash.” Except someone had crossed out the first word and replaced it with something else.
“Nuts must be kept on a leash.”

That sign remained untouched for eight months, until someone sprayed black paint over the offending word.

Now imagine a slightly different scenario. Picture a similar sign on the grounds of a synagogue. If the word “dogs” had been replaced by “Jews,” people would have been outraged. The police would likely have been called. The act would have been described, accurately, as a hate crime. And, rest assured, the sign would have been replaced immediately.

All winter, the sign at the hospital remained unaltered. It would have been impossible for staff to miss it. It would have been impossible for patients to miss it. It would have been impossible for the public to miss it. And yet no one did a thing.

That wasn’t the only sign of stigma floating around. In a 1998 edition of a Toronto tabloid newspaper, there was a story about the Capitol Hill shootings in Washington, D.C., an act committed by a man with schizophrenia. The headline read: “No Hiding from Nutters.” Imagine the outcry had a different ‘N’ word had been used.

A national business magazine ran an ad for a clothing chain featuring a man in a straitjacket. His eyes were bulging, his hair unkempt. He looked, in a Three Stooges kind of way, absolutely and utterly “mad.” Though the intent was humorous, those who’ve been in restraints found nothing to laugh about.

A Saskatchewan radio station used to proudly bill its morning crew as the “psycho club.”

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A Saskatchewan radio station used to proudly bill its morning crew as the “psycho club.” A major Toronto station, during its newscast, reported that Margaret Trudeau Kemper, former wife of Pierre Trudeau, was being held in “the nuthouse.” The Jim Carrey movie Me, Myself & Irene was promoted with the slogan: “From Gentle to Mental.” Entertainment reporters were given press kits with candy “pills” that were jokingly packaged as a “cure” for schizophrenia.

The list goes on. And on.

In isolation, those examples may not appear significant to some readers (which, in itself, is a statement of the pervasiveness of stigma). Together, however, they reflect – and reinforce – an implicit societal belief. It’s okay to treat these people differently. Okay, because they are different. As a document published by the World Federation for Mental Health points out, misconceptions still abound.

“The treatments patients receive may also increase the stigma associated with the illness. Especially if they produce the debilitating motor side effects that can result from treatment with certain antipsychotic medications.”

The Sources of Stigma

Who, as a child, hasn’t called someone a “psycho” or a “schiz?” What campfire would be complete without a story about the axe-wielding lunatic who escaped from the nearby “funny farm?” How many movies have you seen where the villain was not merely bad, but mad?

Stigma has, in many respects, long been part of our culture; an insular, secure world where anything remotely beyond the confines of “normal” can inspire derision, fear, or both. Think of the homophobic AIDS jokes that went around in the 1980s. The not-so-discrete stares people still direct toward those with physical limitations or facial anomalies. The schoolyard chants that continue to ridicule the weak, the geek, the fat, the freak. It seems to be part of our nature to separate “us” from “them.”

We’ve done this on a vast scale with the mentally unwell. Few human conditions have merited such widespread and enduring segregation; much of our treatment this century has been akin to quarantine. Our approach, until a few short decades ago, was to care for people in psychiatric institutions hidden from the rest of the world. Although the intentions may have been honourable, the signal to the public at large was that these folks were clearly very different from “us.” A people apart.

The factors that contribute to stigma are myriad. But it’s worth touching on one more – an ironic twist that can turn into a downward spiral of prejudice and isolation. And that is when the treatment itself marks the person.

A fair proportion of people who’ve been on certain antipsychotic medications develop unwanted movement disorders over time. Involuntary grimaces, pacing, shuffling, or tremors can become quite apparent.

It is these drug side effects – the smacking of lips, the rocking, the restlessness – that fit our stereotypes of “crazy” behaviour. Few members of the public realize that these odd tics are induced by medication, as opposed to being symptoms of “madness.” As the WPA anti-stigma program notes:

“The treatments patients receive may also increase the stigma associated with the illness. Especially if they produce the debilitating motor side effects that can result from treatment with certain antipsychotic medications.”

A Personal Note from Scott

Stigma was, for me, the most agonizing aspect of my disorder. It cost friendships, career opportunities, and – most importantly – my self-esteem. It wasn’t long before I began internalizing the attitudes of others, viewing myself as a lesser person.

In fact, this process began the moment I received a diagnosis. Like many consumer/survivors, I had my own baggage, my own preconceptions of what having a mental disorder meant. And so the stigma I had unknowingly carried toward others was turned inward. Many of those long days in bed during the depression were spent thinking: “I’m mentally ill. I’m a manic-depressive. I’m not
the same anymore.” I wondered, desperately, if I would ever again work, ever again be “normal.” It was a godawful feeling that contributed immensely to the suicidal yearnings that invaded my thoughts.

When the depression finally lifted, I thought I’d survived everything. But being back on the job brought its own moments of purgatory. There is a uniquely penetrating type of pain that comes with silence, stares, awkwardness. The fears I’d conquered, the obstacles I’d overcome, began resurfacing all at once. Over time, I started thinking those people who avoided me in the halls might be right. Perhaps I was now less than I had been. After all, I’d gone crazy. Maybe I even looked “mentally ill.”

But not everyone reacted like that. A few friends and coworkers did something so simple it was extraordinary. They ignored the brand. They still wanted to work together on a story, see a movie, go fishing – hang out. They still saw me.

And because they still saw me, I began wondering what it was all those other people were looking at.

One day, I finally figured it out. I finally understood what they were seeing. A myth.

And that realization was the best of all. Because stigma wasn’t my problem any more.

It was theirs.

* Journalist Scott Simmie is the co-author of three books, including The Last Taboo: A Survival Guide to Mental Health Care in Canada and Beyond Crazy, both of which Scott wrote with partner Julia Nunes. They live together in Toronto, where he’s a feature writer with the Toronto Star. This article is excerpted from The Last Taboo, which was published by McClelland & Stewart. It is reprinted with permission of the publisher. For more information, please see www.goodmentalhealth.info

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**A HISTORICAL CONTEXT FOR MODERN PSYCHIATRIC STIGMA**

Pamela N. Prince *

Due to its etiological link to both biological and social aspects of the human condition, the prevalence of mental illness across cultures gives rise to wide-ranging cultural interpretations and approaches as to how mental illness should be addressed. In this sense, mental illness is a cultural phenomenon, and consequently its social implications are culturally determined. The roots of psychiatric stigma in Western culture can be traced to ancient Greece, where the term “stigma” was initially used to refer to outward physical evidence (e.g., branding) that identified an individual as being of lower moral status. Categories of people such as slaves, criminals, and traitors were thus stigmatized in order to make the status of such individuals readily apparent to others. What we today describe as reflecting a stigma was in earlier eras a natural part of the social cultural landscape, invoked in order to facilitate identification and handling of persons considered threatening in one way or another.2

With respect to illness, the Classical/Hellenistic academic tradition had a fairly holistic understanding of disease. All illnesses, including mental illness, were generally viewed as arising from various humoral imbalances.3 In the larger Grecian social arena, however, cultural values such as reason, individuality, and civic responsibility were highly esteemed. These values were raised as hallmarks of the healthy and virtuous citizen, serving at the same time to set apart, and ultimately devalue, incongruent behaviours and characteristics, such as those exhibited by individuals with mental illness.4

Not surprisingly, it has also been suggested that stigma was intimately linked to the sense of shame that the Greeks associated with illness, and that all treatments were ultimately designed to reduce the shame and stigma that any illness produced for an individual and his or her family.4 In this sense, negative connotations were not exclusive to mental illness. Still, overt ridicule, rejection, and condemnation of persons with psychiatric illness, although evident, was “relegated to those individuals who were poor and chronically ill, … who represented adaptive failures, inability to exist independently, and failure to uphold standards of appearance, dress, and cleanliness.”5

Inasmuch as the cult of individualism is still evident in modern Western society, and particularly in North American culture,6 in many respects the poor seriously mentally ill continue to epitomize society’s “adaptive failures.” Although the cultural developments of ancient Greece are not evidence of stigma being associated with mental illness exclusive of other social factors (e.g., poverty), they may be viewed as precursors to modern psychiatric stigma.2

To the Greek perspective that emphasized humoral imbalances and/or social failure in the case of chronic mental illness, Christian theology added demonism, moral perversion, promiscuity, and sin.7,8 Christian Medieval influence over rational and naturalistic explanations for disease promoted the notion that mental illness represented a test of God’s intentions, a painful ordeal in
preparation for eternal salvation, a warning through example of the power of God, or a frank punishment for evil doings. Association between the demonic and mental illness was established over this period, and insofar as sin was considered the cause of mental illness, individuals with mental illness were indeed stigmatized. Still, religious interpretations did not prevail to the complete exclusion of naturalistic ones and people with mental illness were more or less tolerated during the Middle Ages, especially when compared with the discrimination experienced by lepers and Jews. Further, the stigmatizing impact of Christianity, expressed in terms of banishment, condemnation, and incarceration, applied mainly to individuals who were poor or powerless. In this regard, people with chronic mental illness, perhaps rendered poor and destitute over time, were similarly rejected.

By the Renaissance, the Medieval Christian legacy of guilt and individual responsibility for one’s situation in life made it possible to associate mental illness with other forms of unacceptable behaviour of the day, such as alcohol abuse. As well, political conflicts between Catholics and Protestants in early modern 15th century Europe contributed to the persecution of people, primarily women, accused of witchcraft. These individuals may have been over-represented by already marginalized poor older women, some of whom may have had a mental illness, with the majority more likely to have been convenient victims of misogyny and politically expedient religious persecution. While not evidence of stigma towards mental illness, per se, inasmuch as people were persecuted for alleged witchcraft, these events may have contributed to stigmatizing notions more prevalent in ensuing decades.

The Stigma of Poverty and Mental Illness

As may be apparent with regard to the development of stigma in relation to mental illness, prevailing views may be distinguished among different social classes. Throughout history, mentally ill members of the wealthy and intellectual elite were more likely to be viewed in terms of abstract, literary, metaphorical interpretations of mental illness, and handled with naturalistic explanations of behaviour which considered social and psychological factors. In contrast, poor persons with mental illness were likely to be exposed to harsher realities of life outside the protection of wealth and/or supportive family confines. For example, poor mentally ill individuals were often ridiculed, mocked and even stoned in the streets in ancient Israel, whereas affluent persons with a mental illness tended to be cared for within the protective isolation of their respective families.

Early modern and modern views of mental illness were multidimensional, in the sense that social class, poverty, political and economic factors, and competing medical and psychiatric approaches to illness greatly affected how persons with mental illness were handled. The Church continued to have a strong influence during this period, but central governments were also developing and consolidating their own power. Consequently, and in the face of growing populations, urbanization, and increasing numbers of poor people, the preservation of social order and safety became paramount.

Whereas the seriously mentally ill may have been viewed as socially undesirable and even dangerous in the rural landscape, they were usually isolated individuals, and more or less tolerated. With the growth of urban centres, and attendant efforts to establish administrative guidelines for these emerging city states, classes and groups of people were identified, and consequently stigmatized, as posing a potential threat to social order. These groups typically included the poor and the destitute. Hoards of poor people, exposed by the social and economic inequities of modernizing cities of the Renaissance and early modern Europe, were a major issue for social control. Renaissance views of the poor as masterless, rootless vagabonds, and as such responsible to no one, branded them a serious threat to society. Ironically, this view contrasts sharply with the notion of the spiritually rich pauper who embodied the teachings of Christ and the Franciscan monks. The poor had become objects of fear, and since they were considered less than human, rationalizations for incarceration and cruel treatment ensued. By association through poverty, poor chronically mentally ill persons were similarly viewed and, in addition, subject to interpretations of illness filtered through Christianity and Catholicism, replete with sin and demonism. As a group, the mentally ill were now officially stigmatized, and dealt with through formalized policies, eventually leading to forced incarceration, brutalization, and total institutionalization.

Asylum

In the modern European era, the handling of the mentally ill as a distinct social category took place through segregation in asylums. The reform movement and the moral therapies which took hold in industrializing England are considered to reflect a humanizing element in the approach to treatment of the mentally ill, and this also reflected changing views about the stigma of mental illness. However, as welcome as this humanizing element might have been, it does not necessarily represent a change in the stigmatized status of persons with a mental illness, only in the socially sanctioned response to these individuals. Indeed, “humanizing elements” were not exclusive to the arena of mental illness, but more likely a reflection of a more pervasive and evolving social conscience at work at the time.

The growth of psychiatry as a specialized discipline within medicine was also significant in the history of psychiatric stigma and, according to anti-psychiatry revisionists, combined with the total institution to serve the political and self-interests of the profession. Indeed, a common
A HISTORICAL CONTEXT FOR MODERN PSYCHIATRIC STIGMA

theme of the anti-psychiatry movement, dating back to the late 18th century, has been the objection to psychiatry as a “hospital-centered medical specialty legally authorized to institutionalize and treat patients.” As such, total asylums provided complete control over a group of individuals, guaranteed to be supplied through the political and “policing functions of the modern nation state.” With respect to the impact of institutionalization on modern psychiatric stigma, the social isolation and alienation of people with serious mental illness was effectively reinforced by chronic segregation.

An additional source of social discredit was applied to people with mental illness at this time, arising from the intimation of deception, or fabrication, associated with their inability to work, or to fulfil civic responsibilities such as military service. Indeed, malingering has been credited with fueling modern day efforts to determine objective biomedical markers for mental disease, as well as current requirements that disability be legitimized by the state and by insurance carriers.8

In sum, the stigmatization of persons with mental illness in modern Western culture appears to have emanated from a complex historical evolution combining the Greek cult of the individual, Medieval Christian interpretations of illness as a “turning away from God” (revived by 19th century evangelists), Renaissance social rationalizations for vilifying the poor, the social segregation of the asylums, and the persistent undercurrent of social failure and inability (or perceived refusal) to fulfill social and civic responsibilities. These factors have resulted in a powerful stigma that continues to impact the lives of people with mental illness generally, and those with serious mental illness in particular, as they endeavour to make their way in the community.


PUBLIC EDUCATION IN MENTAL HEALTH

John McCullough

An Opportunity for Change

I am honoured to contribute to this 20th Anniversary Special Report of the Psychiatric Patient Advocate Office of Ontario, and I am very pleased to have the opportunity to reflect on public education in mental health.

It seems to me that advocacy and patients’ rights, both areas for which PPAO stands, are strongly connected to public education. So this is a good forum in which to discuss this subject.

Ontario is at a crucial stage in the makeover of its health care system, including the important area of mental health. The seeds were planted first in connection with mental health care about 40 years ago. The movement away from institution-centred care and toward properly supported individualized community-centred care is at the heart of this makeover.

The reform of Ontario’s mental health system was articulated comprehensively in 1999 in Making It Happen, the province’s vision for coherent, community-based mental health care with excellent, individualized services and service choices, close to home, and with “the consumer … at the centre …(and) able to move easily from one part of the system to another.”

As Chairman of one of nine regional Mental Health Implementation Task Forces, I have had the privilege of learning about mental health from some of the most able and committed stakeholders anywhere. The Task Forces were established to assess local needs, service issues and funding requirements, and make recommendations to the Minister of Health and Long-Term Care on how to effect the transition to a reformed mental health system.

Mental illnesses are pervasive. In its submission to the Commission on The Future of Health Care in Canada, chaired by Roy Romanow, Ontario’s Provincial Forum of Mental Health Implementation Task Force Chairs stated:

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*John McCullough

PSYCHIATRIC PATIENT ADVOCATE OFFICE
Recovery requires society’s acceptance of people with mental illnesses and the active support of their integration into the community. Jobs, housing, services and social life are part and parcel of this acceptance.

Achieving acceptance and integration is no small matter. It is my experience that people hide their true feelings about folks with mental illness and that feelings about integration and true community participation are very mixed.

Nevertheless, without acceptance, living in a community in a way that most of us take for granted simply is not possible. In order to have acceptance, the historic stigma and prejudice connected with mental illness must be eradicated.

Stigma and Discrimination: Public Education is the Antidote

The Romanow Commission referred to mental health as an orphan of Medicare. The stigma and prejudice surrounding mental illnesses are clear, quantifiable and profoundly problematic. A Report on Mental Illnesses in Canada, published by Health Canada in 2002, frames it this way:

- Arising from superstition, lack of knowledge and empathy, old belief systems and a tendency to fear and exclude people who are perceived as different, stigma and discrimination have existed throughout history.
- They result in stereotyping, fear, embarrassment, anger and avoidance behaviours.
- They force people to remain quiet about their mental illnesses, often causing them to delay seeking health care, avoid following through with recommended treatment, and avoid sharing their concerns with family, friends and co-workers.

Knowing this, we have a great opportunity through public education and communication to dispel myths and change public attitudes, all of which will support the recovery of folks who experience mental illness.

At every public briefing session held by my Task Force, public education was mentioned as essential if mental health reform is to be successful.

The impact that education has on acceptance connects it with patients’ rights in the most fundamental way, for there is no right that is more basic than the right to a full life, and there is no way that people with mental illness will be able to enjoy such lives without an understanding and accepting community.

Public Education Targets Everyone

When I speak of public education, I mean the education of both society as a whole and specific groups within society whose perspectives and attitudes can have special implications for recovery.

These groups include opinion leaders in all walks of life, government leaders, teachers, police officers, employers, community and social service providers, mental health organizations, mental health associations, and the general public.
service providers and, indeed, people who experience mental illness themselves, as well as their families.

When it comes to the education of the people as a whole, the main task, clearly, is to eliminate the stigma and resulting discrimination that accompany mental illnesses.

We must make the public aware of mental illnesses, what they are, who they affect, their impact on society, and the fact that people can and do recover. We must inform the public about a broad range of key facts, such as:

- There are approximately 450 million people worldwide currently suffering from a mental or behavioural disorder, according to the World Health Organization.
- Mental illnesses are just that, illnesses. They can be treated and managed like physical illnesses, such as high blood pressure, heart disease and diabetes.
- There are many misconceptions surrounding different mental illnesses that must be dispelled. For example, individuals with schizophrenia are more often withdrawn than violent. The Canadian Mental Health Association further indicates that people with mental illnesses are no more violent than any other group. In fact, they are far more likely to be the victims of violence than to be violent themselves.
- Early intervention and treatment are essential in both stopping the onset of mental illnesses and preventing them from getting worse.

We also must increase public awareness of the strengths, abilities and contributions of people who are struggling with serious mental illnesses. In connection with that, their community visibility must increase. They must be seen clearly on the community landscape and be accepted for who they are.

When it comes to the education of particular groups within the public, a number of challenges must be addressed. We must educate and train police and other social and community services workers to recognize the different symptoms of mental illnesses and respond appropriately. We must educate folks who access mental health services and their families about the changing mental health system. They must be confident that new community-based care will serve them well. And we must educate social workers, psychologists, family doctors, psychiatrists and other mental health service providers of the need to adopt best practices in mental health care, and provide them with the necessary tools to do the job.

**Education Is Key**

Education can help drive the profound change needed to help those with mental illness recover and reintegrate into the community. But other important steps will have to be taken with respect to such basic needs as housing, funding, and employment supports. Nevertheless, education is, and will continue to be, a key ingredient in the mix.

I don't know that anybody has done, or can do, a tally of the resources that are invested in mental health education in Ontario. I am confident that a strong case has been made for new investment in public education. I know that society would benefit, groups would benefit, and most importantly, folks who experience mental illnesses and their families would benefit from a public education program aimed at eliminating the associated stigma and discrimination. Public education is an investment in our future, not a cost!

I am equally confident, however, that we could realize better value from the investment we're making right now by coordinating our efforts more effectively through the sharing, coordination and distribution of materials, and by partnering in new ways.

I would like to see folks who use the mental health system become more active in public education. I can't imagine anything more compelling, instructive or constructive than people with mental illnesses sharing their life experiences and challenges with school and community groups.

I would also like to see new corporate partnerships in public education. Some of the disability insurance companies are becoming more active. They have a business reason for this activity, and that is all to the good, but they could do more.

Irrespective of the initiatives we choose, I believe we have an opportunity before us to pull together as never before to maximize the value of current education efforts and, perhaps, to produce new high-impact initiatives that could be undertaken for relatively modest costs.

I call upon those in the system to provide the leadership that is needed to seize this opportunity!

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*John McCullogh, Chair, Communications Steering Committee, Provincial Forum of Mental Health Implementation Task Force Chairs and Chair, Mental Health Implementation Task Force Central East (Penetanguishene) Region.*
Mental Health Issues for Persons with a Dual Diagnosis: A Family Perspective

Jim and Elgi Johnston

Families who have an adult child with a dual diagnosis (an intellectual disability and mental health needs) struggle to access services or even to know what services are available that would help them support the individual. There are two major systems to navigate – mental health and developmental services. Supports are not keeping up to demand. There are over 600 individuals with a dual diagnosis waiting for residential services in Toronto alone. Any family dealing with an adult child with an intellectual disability is under great stress, and adding mental health issues is often enough to break down the family unit. Since current estimates are that upwards of 30% of those with an intellectual disability have mental health needs, the problem is acute and growing.

The family can be the most powerful positive influence in the support of an individual who has a dual diagnosis. In fact, the family is often the only one that is able to find and coordinate the services that the individual needs. To ensure that this happens, the family needs information and support from experts in the field. All too often, these experts focus on the individual needs. To reverse them. In fact, there may be an underlying stress of having to cope with the loneliness and rejection that impacts those who have an intellectual disability, and the lack of meaningful day program opportunities.

Mental health problems often develop as the individual reaches maturity. Sometimes, in fact, these problems are attributable to the stress of having to cope with the loneliness and rejection that impacts those who have an intellectual disability, and the lack of meaningful day program opportunities.

The mental health symptoms may be mistakenly seen as related to the intellectual disability. That is, if the family member is impulsive, withdrawn, or irritable, symptoms may be attributed to the disability, and an assumption made that there is little that can be done to reverse them. In fact, there may be an underlying physical illness, a life crisis, a psychiatric illness, or a stressful environment.

Normally, support for the individual with a dual diagnosis, if available, will come from the developmental sector in the form of day programs or residential placements. Workers in that sector do not have the specialized training to recognize mental health issues and to effectively counsel the family concerning them. In fact, the low pay scales for these workers and the resultant lack of capable young men and women who want to enter the field is alarming.

Families are also concerned with a lack of flexibility in the system. Many programs are not designed for the individual, but rather try to force-fit the individual to the program. Families will deal with one agency, but that agency is often unaware of what programs other agencies have to offer. As a consequence, a family will not be aware of other programs that could meet the needs of their adult child much more effectively. Even if the parent becomes aware of a better program there is no process for the family to evaluate the program and to transfer to another funded agency. Many families are looking for practical training that will help the adult child cope in society. Training in cooking, laundry, or personal hygiene, for example, may not be available from the agency supporting the individual.

Some families want to design an individualized program themselves which will fit their child’s needs. The Government of Ontario has experimented with individualized funding where families apply to have the government fund certain specialized services that are otherwise unavailable and that the family would supervise. Although the pilot has been extremely successful for the families that participated, and is as cost effective as many agency-run programs, the government has not moved to expand the concept.

Support for assessment and diagnosis is difficult to find. The developmental agencies are not equipped to deal with a significant mental health problem, and the community mental health agencies will usually refer the individual back to the developmental sector. The linkage between developmental services and mental health services must be strengthened so families can receive a full range of supports regardless of the service the family accesses. The agency that the family deals with must be able to understand and access a wide range of services for that family.

Unfortunately, there are very few psychiatrists in the province who are competent in the field of dual diagnosis. Education for psychiatrists in the field of intellectual disabilities is sadly lacking. Medication often becomes the panacea.

In many cases, families are not informed adequately about the possible side effects of the medication, or what alternatives exist. Attempts are made to reduce symptoms by an increase in dosage instead of a more thorough assessment. Many families resort to reducing the dosage or discontinuing the medication on their own to determine what will work for their adult child.
The family needs access to a coordinated assessment of the individual, where medical, developmental, and mental health factors are all assessed and integrated so that an effective plan can be created. Very few families are able to get a good assessment. Instead, they get incomplete input from various sources (family doctor, developmental agency, etc.) and then struggle to make sense of the input.

Families do not see ongoing coordinated support from medical, developmental, and mental health professionals. Symptoms are often seen as behavioural problems and dealt with by behavioural management tools. In most cases the family does not know how to navigate the mental health system. Possible medical conditions which may be affecting the individual may not be discovered. For example:

- An individual slapped her abdomen over a period of time. It was seen as a nervous habit or attention seeking and efforts were made to stop her slapping. The woman had an ulcer.
- An individual raised his hand over and over, and was told to keep his hand down. He was having a heart attack.
- An individual seemed unresponsive and uninterested in tasks he was capable of doing. He had a sleep disorder.

As this population ages, diagnosing mental health and medical issues will become even more critical.

Inevitably, an incorrect diagnosis, and therefore the wrong interventions, will lead to a crisis. This will put extreme pressures on the family unit. The ongoing stress of supporting the adult child impacts all the members of the family, and without support the family itself is in danger of not being able to support the individual. The family must receive support to recognize impending crises, intervention to prevent them and information about what resources are available to help should crises develop. The “safe bed” initiative is a great help to families who find their child in crises, but it is a short-term solution and does not help to prevent such occurrences.

From the family’s point of view, the “system” seems fragmented and often unable to provide assistance. They need help to make sense of the system and to find the appropriate supports. Case management can be helpful, but only if the case manager has a broad understanding of both the developmental and mental health sectors.

Funding from “Special Services at Home” is one way for families to access workers who may be used for respite or for particular skills development. Recently, headway has been made in creating a respite system that will help families to locate these workers. Finding workers who are competent to deal with an individual with a dual diagnosis, however, continues to be a significant problem for families.

Since there are few standards of quality for agencies in the developmental field and no requirement for certification, the quality of programs varies considerably from agency to agency. Parents often recognize this lack of quality, but may not know where to turn or may feel that there will be repercussions from complaining. There needs to be certification for agencies that deal with this most vulnerable population. In addition, there should be a clear way for a family to escalate their concerns beyond the agency with assurances that no repercussions will occur. Agencies all feel that their programs are excellent, but with no objective independent measurements, each agency is left to evaluate their own program, and only improve it if they see fit. The provincial government should take a leadership role in setting clear standards, and ensuring families understand how to escalate their complaints.

In summary, families need:

- To be able to access coordinated assessments.
- To have government recognize the value of trained workers in this field, and make their pay competitive.
- To have accreditation of agencies so that families will have some guide as to the quality of the agency.
- To have flexibility in the support of their adult child, including individualized funding and the ability to move to alternate programs if required.
- To have access to knowledgeable case managers who can help them navigate both the developmental and mental health systems.
- Assurances that proper support will be available when they can no longer support their adult child.
- To have the medical profession and medical schools recognize the lack of psychiatric and medical expertise in this field, and provide the necessary education.

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Mental Health and Patients' Rights in Ontario: Yesterday, Today and Tomorrow

Mental Health Services: Issues and Difficulties from a Family's Perspective

Tony and Sandra Cerenzia*

If I had a crystal ball, I wouldn’t look into the future, it might look too much like the past!

Our society has long cautioned families about the trials and tribulations of “the teenage years,” but when your teenager is diagnosed with a severe mental illness like schizophrenia, the entire family is faced with challenges which seem (and sometimes are) insurmountable and questions which need (and sometimes don’t have) answers. What is this illness? Where do you get help for your family member – and yourself? Why aren’t you as a family getting more support? What does the future hold? This article shares the thoughts of one family about the seldom discussed issues that underlie some of the difficulties which surround mental health services.

When our son, Steve, was first diagnosed with schizophrenia twenty years ago at age 16, we weren’t surprised; we weren’t even particularly worried. We knew something was seriously wrong and accessed a psychiatrist early in the illness. A tentative diagnosis, medication trials under close scrutiny, total recovery, weekly then monthly family office visits with the psychiatrist followed – exactly what we expected. The treatment was successful; the medication was discontinued – and Steve had a relapse from which he did not recover! That was the first step from the “health care system” to an alien one – the “medical health care system.” That was the first step from a system that recognizes and understands symptoms; treats and protects patients; supports, values and informs families to a system where rights replace treatment; where consumers/survivors replace patients; where family alienation and blame replace inclusion and support. That was the first step into a system wrought with challenges, frustration, and pain!

If families were not exhausted, they could write volumes about the difficulties encountered when they have a family member who enters the mental health care system. However, these difficulties will not be rectified until there is an understanding of the rarely discussed issues that underlie them.

The first issue is a fundamental flaw in the system’s philosophy, as exemplified by the generic term “mental illness.” All mental illnesses are not the same. The term “mental illness” lumps together a variety of disorders, such as schizophrenia, post-traumatic stress syndrome, depression, personality disorder, stress on the job – some which are neurobiological, some of which are experientially induced; some which require medication, some which benefit from counseling; some which can be prevented, some which cannot; some which are acute, some which are chronic; some which affect the ability to think and behave in a rational manner, some which do not impair cognitive functioning. By using the term “mental illness,” the mental health care system implies that “one size fits all” as regards the care, treatment, and services needed; this is the message it gives to policy makers and the community. This is no more logical than lumping together cancer, diabetes, and a broken leg! As a result of this philosophy, planning and decision-making are done by committees representing geographic regions and heterogeneous community agencies rather than by specialists in specific disorders.

Once it has been recognized that all mental illnesses are not the same, issues involving specific illnesses (for example, schizophrenia) can be defined. Schizophrenia is a chronic neurobiological illness. Still, families and patients affected by schizophrenia experience barriers to care, treatment, and support which those with other biological illnesses do not. Because of the fear, stigma, and lack of knowledge that exist surrounding this illness – not only in society, but often among health care professionals – families are reluctant to consult a physician, physicians are reluctant to make a diagnosis, and hospitals are reluctant to admit the ill person. Rather than “early intervention,” it is often “police intervention” that families must ultimately resort to as the first step toward receiving treatment. When long-needed hospital admission does occur, it is often through a revolving door, with the person discharged without having received the necessary treatment. Instead of health care professionals understanding the impact that schizophrenia, like any other serious illness, has on the family and the family’s need for information and comfort, too often “patient confidentiality” becomes a convenient method for dismissing family involvement – even when it would be in the best interest of the ill person. The term “medical model” has become an anathema among many. It may seem simplistic, but a medical condition must be treated medically. The medical model does not preclude the need for people with schizophrenia, or with any other medical condition, to address social, emotional, physical, or cognitive needs resulting from their illness.

The provincial government has identified the needs of the severely and persistently mentally ill (which most often translates into people with schizophrenia and bipolar disorder) as being its primary focus in mental health reform. This focus has two major cornerstones. The first cornerstone is decentralization of tertiary care services – getting people closer to home. In other words, at the same time that concern is being expressed that ill people already in their home communities are not being served, plans are being made to return more people to their home communities. The needs of the widely dispersed mentally ill are expected to be served by “equity of service” – a
popular catchphrase. This raises a third issue – one of “equity vs. excellence.” Heart bypasses are not performed closer to home; bone marrow transplants are not done closer to home; brain tumors are not removed closer to home. Why not? For treatment to be successful for any severe illness, there must be a critical mass of patients, teams of specialists, and a research centre. Furthermore, ill people must receive what they need – not what is the same as others receive. The emphasis in care and treatment should be on excellence – not equity. The two are incompatible.

The second cornerstone of mental health reform is movement from the tertiary care hospital to the community. This is a worthy goal. However, the community services that are in place do not support that movement. The severely mentally ill are incapable of phoning a crisis line, need more support than is provided by a case manager, and are unable to perform the daily living skills required to live independently. They need assertive community treatment (ACT) teams, supportive housing, and, in some cases, 24-hour supervision in order to be safe and have their needs met. These services cost money, but so do chemotherapy, organ transplants, and dialysis. Caring for its most vulnerable citizens, regardless of cost, is the mark of a civilized society.

A further issue is the unnecessary chasm between the consumer/survivor movement and the family movement. This is perhaps the most surprising, incomprehensible and distressing aspect of the mental health system for parents when they enter the system. The roots of this chasm appear buried deeply in the past with Sigmund Freud, who blamed parents (especially mothers) for their offsprings’ illness, and with families who, not knowing what else to do and in keeping with the times, worked with psychiatrists to commit their ill family members to asylums which were less than desirable places.

More currently, many consumers do not want family involvement because they: 1) have come from abusive family backgrounds, and/or 2) want to make their own decisions. This is another example of why it is essential to differentiate between mental illnesses. Regarding the first reason, there are many people who are mentally ill as a result of family abuse, but there are also many who come from loving families. The former group have every right to refuse family involvement, but involvement of families of the latter group should be encouraged - as it is for other illnesses. Regarding the second reason, the cognitive ability of the majority of people experiencing mental illness is not affected. This allows them, as they should, to make decisions about their treatment and lifestyle, as they understand the consequences of their decisions. However, there are some people, such as those with severe schizophrenia, whose mental illness interferes with or prevents their ability to make sound judgments. These are the people for whom families should, unless there are indications to the contrary, make decisions. Just as families should not make decisions for consumers who are able to do so for themselves, consumers who are cognitively intact should not make decisions for those who are not cognitively intact, nor should they advocate for or against laws which do not impact on their own well-being, but do on the well-being of others. Through communication and mutual respect, families and consumers can be mutually supportive, not adversarial, as they share a common goal – what is best for the person who is ill.

An overriding issue (and terror) for families of the severely and persistently mentally ill is, “What will happen to my ill family member when I am no longer able to care and advocate for him?” In other words, what does the future hold in mental health care? There are two possible scenarios. The first is the “modified status quo scenario,” in which the major service change is “lip service” - in which people are moved from the hospitals into the streets, the prisons, and the morgues. The second is the “paradigm shift scenario,” in which dollars and focus will be on the needs of the severely and persistently mentally ill rather than on existing services. This will result in acceptance of severe mental illness as a biochemical brain disorder; understanding of severe mental illness by key community players (e.g., police, courts, teachers, health care professionals); evidence-based services and treatment; support, education, and empowerment of families as lifelong caregivers; improved quality of life for families affected by severe mental illness; the removal of stigma; and research resulting in a cure. People will not be ridiculed and criminalized when they are already the victims of an illness. Families will not be ashamed to speak out; they will be able to live and die in peace.

In summary:

- All mental illnesses are not the same.
- Families and patients affected by severe and persistent mental illnesses experience barriers to care, treatment, and support which those with other biological illnesses do not.
- Equity and excellence are incompatible.
- Cost should be no more a factor in caring for the severely and persistently mentally ill than it is in caring for people with other biological illnesses.
- Consumers/survivors and families should not be in adversarial positions. They share a common goal – the highest quality of life possible for persons who are mentally ill.
- A paradigm shift based on consumer needs and evidence-based services is necessary for successful care for the severely mentally ill.

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The first experience of a serious psychotic illness is traumatic for the person experiencing the psychosis, and for his or her family. The onset is often insidious, with a spectrum of non-specific prodromal symptoms that cause confusion and perplexity for the whole family. But once the psychotic symptoms have become florid, there is usually not much doubt about what should happen. The person needs hospitalization and treatment on an emergency basis. The onset of frank psychosis can be compared with a physical emergency such as a heart attack. Let’s look at how the two conditions are managed in our health care system.

A Health Emergency: The Right to Timely Care

Someone experiencing chest pain (a prodromal symptom of heart attack) is immediately recognized as a medical emergency. The family calls 911, the patient is transported with sirens blaring to the nearest Emergency Room. Triage immediately bumps the person up to the top of the list. A quick diagnosis of MI (myocardial infarction); cardiac enzymes are sent off for superfast readings, and if positive for MI, anti-clotting therapy is immediately instituted. When things are under control again, rehabilitation is prescribed, and the patient and family are given support and counselling about how to help the person recover fully.

And what of the other type of MI (mental illness)? Just like a heart attack, the psychotic patient’s immediate needs are prompt care and treatment. Just like a heart attack, evidence is beginning to show that the earlier treatment is instituted, the better the outcome. But what actually happens?

The family takes the person to hospital – if the latter can be persuaded to go! Triage will immediately relegate this emergency patient to the bottom of the waiting list. Hours pass, during which family members expend all their energy on preventing the person from leaving before being treated. If the family succeeds, eventually the person will see a doctor, who may do a quick mental status exam without even asking the family what his/her symptoms are. He/she is being convinced that his rights may be being violated! The family often sees this as yet another delay in getting their loved one on the way to recovery. In a physical illness the patient gets a reasoned description of probable treatment outcomes. If you take the meds, the psychosis will resolve and rehabilitation can begin. But if you don’t take this the psychosis will deepen, you have no chance of recovery and you may suffer irreparable brain damage. Research is beginning to show that psychosis, like anoxia, damages the brain.

With any illness the aim should be prompt and comprehensive treatment so that recovery is possible. This can happen when, as in heart attacks:

- the public has a clear idea of where to go, or where to take someone whose mental functions appear to be grossly abnormal;
- medical personnel listen to accompanying relatives’ descriptions of symptoms and behaviours observed;
- treatment options and outcomes are clearly stated along with side effects or possible negative outcomes; and
- there is no delay before effective medical treatment.

Does the public have a clear idea where to go? No, those with no previous experience with the mental health system do not know where to go. Studies of first episode psychosis patients and families reveal that, even after they realized that something was seriously wrong, up to
two years can elapse before the person reaches treatment. Stigma prevents the family from admitting that what they are seeing is a mental illness. Then they go the usual route of trying to find explanations for the behaviour they are seeing. They consult their friends, they consult their child’s teachers, they consult their minister, rabbi or imam, they consult other community agencies. They consult their family doctor… And far too often, none of these people can help. They don’t recognize the symptoms, they don’t understand that prompt treatment will bring a better outcome, they don’t know where prompt treatment is to be found.

Contrast this with the general public’s knowledge of heart attacks. Everybody knows that chest pain equals heart attack; that the fastest possible presentation at an Emergency Room leads to a better outcome; and that the quicker medication can be administered the more likely the person is to survive with minimal damage. I’m sure if you passed someone on the street clutching his chest and complaining of pain, you would punch 911 on your cellphone and get the ambulance there. Why don’t we do the same for someone staring into space talking to themselves about aliens who are plotting against him?

The Mental Health Act has been amended in ways that families hoped might facilitate access to prompt care for people whose illness affects their judgment to the extent that they do not understand they are ill, or irrationally fear doctors and hospitals. The chief advantage of the recent (2000) changes to the Act is that Forms 1 and 2 can now be signed for a person who is mentally deteriorating before violence occurs. There is a flaw in the “new” Act – these grounds only apply to people with a known history of successful treatment of their mental illness. Those families dealing with psychosis for the first time, who cannot persuade their loved one to go for help, still have to wait until fear, threat, or violence precipitates police action.

One hundred years ago, or even 50 years ago, it is probably true that mental patients were abused, had no rights or dignity, were locked up against their wills, and never got back to real life. There were some very real wrongs that needed to be righted. Because of 20 years’ work by the PPAO there is now a plethora of safeguards in the Mental Health Act and the Health Care Consent Act that protect vulnerable people from intrusive incarceration. But those aren’t the human rights that families most fear will be violated. What we fear is that the right to refuse treatment will override the right to prompt effective treatment and the opportunity to recover.

Today, in 2003, we at the Schizophrenia Society are concerned about the mentally ill person’s human rights as a person, not as a mental patient:

The Right to Adequate Income
Disability supports in this province, and others, are woefully inadequate; the Ontario Disability Support Program is punitive to access; the system is stigmatizing and is structured to constitute a disincentive to recovery.

The Right to Good Appropriate Housing
Do we have to repeat this? Since 1995 virtually no new low-income subsidized housing has been provided. People with severe mental illnesses such as schizophrenia need a range of differing housing types, depending on the degree of severity of functional cognitive disability. Most people with schizophrenia still live with their families, not because this is the best place for them to learn and achieve independence, but because the alternatives are unaffordable and unacceptable. Boarding homes where standards of care are inadequately enforced, homeless shelters, and the street are not acceptable housing. The ground is now paved with studies outlining the housing needs of the mentally ill population. But where is the housing?

The Right to Access to Employment
Perhaps at least one-third of all those diagnosed with an illness as severe as schizophrenia will recover to the point where they can work. But what work is available? And how sensitive are mainstream employers to the accommodation needs of people with a serious and persistent mental illness? Welcoming back an employee who has recovered from a major depression, maybe. But making allowances for someone who has concentration difficulties, who has social deficits, and can’t complete a moderately complex task without continuous close supervision – this is very rare indeed. A few consumer initiatives with government subsidies are doing good work, but what is needed is mainstream employment.

The Right to Full Acceptance in Society
The Schizophrenia Society of Ontario looks forward to a day when people with the most severe mental illnesses, such as schizophrenia, can live as full citizens of our society with all the rights everyone else enjoys. They will not live or work in a mental health ghetto, but in the same environment as others. They will be accepted as equals, without stigma, in all corners of a caring society. And when health care is needed, they will receive it as promptly as everyone else.

2 Section 20 of the Health Care Consent Act, S.O. 1996, c.2, Sched. A, sets out a ranking of substitute decision-makers (SDMs). An incapable person’s court-appointed guardian or attorney for personal care with authority to consent or refuse the proposed treatment, and a personal representative appointed by the Consent and Capacity Board, all rank ahead of family members. In practice, few individuals will have any of these in place, and a family member typically become the SDM.
MENTAL HEALTH LAW IN THE COMMUNITY: A RIGHTS PROTECTION FRAMEWORK THAT FALLS APART?

Jude Bursten∗

Mental health reform has signaled an unprecedented movement of patients from inpatient to outpatient settings. The downsizing process is intended to reintegrate persons with severe and persistent mental illness back into communities where services are presumably enhanced to provide a continuum of care based on the core components outlined in Making It Happen. The system is designed to provide a seamless shift from hospital to community, with a focus on implementing individually determined measures to reduce the likelihood of readmission.

Although the driving forces behind this provincial initiative have been to operationalize best practices in mental health service delivery, to facilitate regional autonomy in the identification, planning and provision of community services, and to focus on improving quality of life through a client-centred approach to care, there is an absence of corollary legislative measures to ensure clinical accountability and rights protection in a community setting.

The relationship between the protective interests of the state and the rights of the individual is well established in the context of mental health law. Ontario has a rich history of balancing the tension between the protection of patient rights that preserve autonomy, dignity, privacy, and access to care with public interest and safety through legislative safeguards. This balance serves as an accountability mechanism by ensuring the state does not arbitrarily detain, impose treatment or otherwise exert control over citizens. The Mental Health Act concretizes this critical component of state accountability by mandating nine circumstances in which a person must receive formal rights advice regarding a change in their legal status. These include:

1. When a person is made an involuntary patient (ss. 38(1)) (Form 3);
2. When a patient’s involuntary status is continued or renewed (ss. 38(1)) (Form 4);
3. When a patient has been found not capable of managing his or her property and a certificate of incapacity or notice of continuance has been issued (s. 59) (Form 21 or 24);
4. When a patient has been found not mentally competent to examine his or her own clinical record in the facility (ss. 38(4)) (Form 33);
5. When a patient has been found not mentally competent to disclosure of his or her own clinical record to a third party (ss. 38(4)) (Form 33);
6. On the admission of a 12- to 15-year-old informal patient (ss. 38(6); ss. 13(1)) (Form 27);
7. Every three months following the admission of a 12- to 15-year-old informal patient;
8. When a patient is determined to be incapable with respect to treatment of a mental disorder (under the Health Care Consent Act2), in circumstances set out in the regulations under the MHA (Form 33);
9. Before issuing or renewing a community treatment order (CTO), a physician must be satisfied that the person who will be the subject to the CTO (and his or her substitute decision maker, if applicable) have consulted with a rights adviser and have been advised of their legal rights (s. 33.1(2)) (Form 49).

In all of these situations, formal rights advice is only provided to those persons whose care and treatment are under the jurisdiction of a scheduled facility prescribed in the MHA. In December 2000, amendments to the legislation extended the formal component of rights advice to those persons subject to CTOs who might otherwise meet criteria for detention. The person subject to any of these changes to legal status must receive written notification from the health care practitioner making the finding. In addition, a rights adviser must be notified in order to provide information on what the certificate means and what options are available should the person disagree with the health practitioner. Documentation that the rights adviser has provided this information must be placed in the person’s clinical record.

In some of these circumstances, the change of legal status is confined to hospitalization and one’s status as an inpatient. For example, certificates of involuntary and informal admission are issued for prescribed periods of time and based on specifically articulated criteria. Additionally, a certificate of incapacity to manage finances issued during hospitalization confers an obligation for further assessment and renewal prior to discharge in order for this incapacity status to be continued in a

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† The Mental Health Act concretizes this critical component of state accountability by mandating nine circumstances in which a person must receive formal rights advice regarding a change in their legal status.
community setting. The right of an individual to challenge a change in legal status is clear and unequivocal while that person is considered to be a “patient” within the meaning of the MHA.

These formal safeguards, however, appear to erode in community settings. The PPAO recently conducted and evaluated a pilot project in Eastern Ontario designed to examine the advocacy and rights related issues experienced by clients and clinicians of Assertive Community Treatment Teams (ACTT). The project findings in addition to advocacy issues generated outside the purview of the pilot highlight a critical need to review the legislative framework guiding clinical care and accountability mechanisms to enshrine rights protection in non-hospital settings. Although the target population of this project was specific to ACT team clinicians and clients, issues identified that relate to rights protection are germane to all service delivery models where formal rights advice is not provided.

**Voluntary or Involuntary?**

One core component of the ACT philosophy is that participation is voluntary. A second core component is that the service engagement process is assertive. Taken together, these potentially antithetical components can obfuscate the line between informed, voluntary participation and acquiescence to an assertive engagement process that may be perceived by the client as coercive or “involuntary.” This situation may be exacerbated for those clients subject to a community treatment order (CTO), where receiving ACT services is a component of the Community Treatment Plan. To date there are no formal measures to ensure clients are advised of their right to refuse service or conversely to appeal a decision where service is denied.

Some teams were unclear about the boundaries of their service mandate, especially related to access and privacy rights of clients refusing service. Entering a client’s home or room without permission or gaining access through other intrusive measures not only blurs the line between voluntary and involuntary, but suggests that tenancy rights may be compromised because these rights have not been explained or codified through tenancy agreements.

**Property**

The obligation to assess a patient for capacity to manage property forthwith upon admission is enshrined in s. 54 of the MHA. Where a certificate of incapacity has been issued, s. 57(1), there is a requirement for the physician to re-examine the patient within 21 days prior to discharge and, if applicable, issue a notice of continuance with respect to the finding. These certificates confer formal rights advice and access to a review before the Consent and Capacity Board.

Several barriers to protecting the rights of patients discharged on a notice of continuance have been identified. Historically, the law was interpreted to provide a person on a notice of continuance the right to challenge this finding up to six months after the certificate was issued. A recent decision by the Consent and Capacity Board, however, provides an interpretation of who may apply for a review, based on a critical review of the language of statute. The Board concluded that the right to apply for a hearing set out in subsection 60(1) is restricted to persons who are “patients” for the purposes of the Act and that the definition of patient set out in Section 1 of the Act is clearly limited to persons who are “inpatients.” Thus a patient must apply for a hearing prior to being discharged or forfeit the right of review. In this same decision, the Board determined that a failure to provide the client with written notice of the finding or access to rights advice vitiates the finding of incapacity.

Often patients are discharged to the community while on a leave of absence from the hospital. When a notice of continance is issued in these circumstances there is neither provision for rights advice nor assurance that the person received written notice. Despite the Board’s ruling that failure to follow such procedures renders the Certificate void, there is no requirement for the Public Guardian and Trustee to ensure legislative compliance prior to assuming that their jurisdiction is legal or valid.

Despite the rigorous legal requirement for physicians to assess and review financial capacity during hospitalization, physicians in the community, serving these same clients, have no authority to either make a finding or revoke a pre-existing finding of financial incapacity. This limitation has created frustration for both physicians and clients.

Physicians are confronted with circumstances of deterioration on an immediate basis where the authority to make a finding of incapacity could prevent hospitalization or housing loss. Conversely, for those clients who become stable and could be determined capable, the process for such an assessment is independent of a protective, therapeutic milieu attendant with the physician/client relationship. Regardless of the intent, accessing a capacity assessment is not straightforward. The process requires informed consent of the client, which may be difficult to obtain if the assessment is in adverse interest to the client’s wishes. Some physicians have requested that clients be admitted for the sole purpose of assessing capacity to manage finances. In other cases, informal measures of controlling finances are employed, such as disbursements of a per diem allowance by landlords, where accountability and legal recourse for the client are absent.

Clients in the community who wish to have a hearing on the Notice of Continuance issued at discharge must have a further capacity assessment before the application will be heard. This assessment is at the client’s expense. Information regarding the process is not well understood and is perceived to be too complicated. This serves as a disincentive to pursue.
**Treatment**

Ontario legislation confers an obligation to obtain informed consent before any treatment may occur: either from the person receiving treatment or, if there has been a finding of incapacity, from the person’s substitute decision-maker (SDM). The legislative requirements regarding treatment incapacity in facilities governed by the MHA include a formal finding with notification to the patient, informing a Rights Adviser and confirmation that rights advice has occurred. These formal components and levels of accountability do not apply in community settings. Treatment incapacity is noted on the chart and although there is no legislative requirement for independent rights advice, there is a statutory obligation requiring the health practitioner to provide information to the person or his/her SDM on what the finding means and options should the client disagree. Generally, substitute consent must be in place prior to treating the incapable person with rare exception such as an emergency.3

The issue of who has the authority to make a finding of treatment incapacity is not well understood in the community. The HCCA provides that only the treating physician has full knowledge of the elements of treatment required to satisfy the two-part test for capacity. Thus, for example, capacity to consent for surgery must be assessed by the practitioner proposing surgery. Often, however, physicians diagnosing and treating medical conditions make referrals to psychiatrists to make a finding of incapacity, believing that the presence of a mental illness is the basis for a determination of capacity regardless of the medical condition or the proposed course of treatment.

These issues are somewhat alarming. In the limited context of the pilot advocacy project, the confusion regarding treatment incapacity was repeatedly identified and redressed. In the absence of concrete accountability or audit mechanisms, there is no way to assert that capable clients are able to refuse treatment, that informed consent is obtained or that health care practitioners advise incapable clients of their rights. Clients with questionable capacity issues, complex medical problems, and a limited resource base from which to question authority or access information should be able to expect and rely on a system of health care integrity regardless of the setting. At minimum, this should include a mechanism to ensure compliance with legislative requirements.

**Access to and Disclosure of the Clinical Record**

The MHA has special rules that govern access to and disclosure of the clinical record. These rules are safeguards to ensure that confidential health information is protected. The clinical record includes all or part of a patient’s record compiled in a psychiatric facility. Patients who are competent can give consent to disclose the record. Patients who are determined to be incompetent to consent to disclosure must be given written notice of this finding in addition to formal rights advice. Similarly, a patient made incompetent to access their clinical record will be notified in writing and receive rights advice.

A competent patient may apply to access his or her clinical record. This right of access must be granted unless the hospital has written direction to withhold all or part of the record from the Consent and Capacity Board, based on evidence that the access to the record will likely result in serious harm to the treatment or recovery of the patient while in the facility, or serious physical or emotional harm to another person.

The safeguards do not apply to records held by facilities or community agencies that are not designated psychiatric facilities under the Act. There are no standardized protocols to ensure a client’s right of access, nor principled measures of appeal when this access is denied. Further to this, findings of incompetence to access or consent to disclosure of the record are not formal procedures and as such confer no recourse to a client, unless this recourse is individually determined by policies established by the agency maintaining the record. The Consent and Capacity Board has no jurisdiction in such cases. A client may not even know that a finding of incompetence to access or disclose the record has been made.

Issues related to disclosure of records have mushroomed in community settings. In efforts to provide seamless continuity of care, agencies have attempted to find creative measures to communicate when client care is shared between and among services. Despite the fact that the Form 14, Consent to the Disclosure, Transmittal or Examination of a Clinical Record, is intended to protect such records in facilities governed by the MHA, this form is routinely misapplied to records held in community settings. Protections for client confidentiality are often misunderstood, as evidenced by the number of inquiries regarding disclosure issues. For example, health care practitioners have expressed a sense of obligation to disclose client criminal behaviour to the police, even though this obligation does not exist and may be a contravention of privacy rights and professional regulations.

**Conclusion**

Rights protection is enshrined for patients in psychiatric facilities under the MHA. The downsizing of these facilities and subsequent growth of care models in the community have rendered such protections vulnerable. Clients served in community settings should have the same access to information required to make informed decisions regarding services, treatment, and care as inpatients of psychiatric facilities. Without these formal rights protection measures, clients may be routinely subjected to well-intentioned but abusive abdication of clinical responsibility without due process recourse. The
legislative framework designed to safeguard the balance between citizen autonomy and State control in community settings has tipped in favour of the State.

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**DEVELOPMENT OF ASSERTIVE COMMUNITY TREATMENT TEAMS IN ONTARIO’S MENTAL HEALTH SYSTEM AND THEIR IMPACT ON MENTAL HEALTH SERVICES AND PATIENTS’ RIGHTS**

Hugh Lafave, † Gary Gerber, ‡ Henry de Souza, § Sheila Miller § and Frank McPherson ††

A paper entitled “La fin de l’asile,” written in 1974, made predictions about the future of the mental health system that were optimistic, flamboyant, and sadly, not very accurate. The paper described the process in which a large hospital was phased out entirely in favour of community services comprised of multi-disciplinary teams that were within a 45-minute drive of any user. Findings of follow-up studies of persons moved from the hospital to community settings were very favourable. For example, there was not a single suicide or serious crime reported for the 200 persons selected for a five-year follow-up study. Fewer than half of the group were readmitted to a hospital setting for brief periods of time in the five years following their move to a community setting. Admissions were made to a general hospital psychiatric unit rather than to a mental hospital. Less than 2% of families interviewed at follow-up felt that their family members were not better off in the community than they had been in hospital. These same families also did not feel that they were better off with their family member living in the community. Costs of community care were shown to be less than costs of care in a mental hospital.

Marx, Test, and Stein formalized the concept of a community team in Wisconsin in the 1970s. The effectiveness of community teams, compared to hospital treatment, was clearly established by Stein and Test. Based on the favourable evaluations of Program of Assertive Community Treatment (PACT) teams, this concept was disseminated through the United States, so that there are now more than 1000 assertive community treatment teams (ACTTs) in operation.

In spite of these developments in the United States, there were no ACTTs in Canada. The first author obtained funding to develop the first ACTT, established in eastern Ontario in September 1990. This team was immediately successful in preventing hospitalization of consumers and in supporting other consumers discharged after long histories of hospitalization. A one-year follow-up study found that consumers randomly assigned to the ACTT were able to remain in community settings most of the time, and reported better quality of life than consumers randomly assigned to treatment in a psychiatric hospital. These initial results led to funding of a second ACTT, and there are now over 60 such teams in Ontario. Other provinces have followed suit and established local ACTTs.

There have been substantial changes in the Ontario mental health system since 1990. While the changes are due to several factors, the introduction of assertive community treatment is responsible for many of these developments. No longer are mental health consumers routinely transferred from a general hospital to a psychiatric hospital after a few weeks of treatment. No longer are consumers returned to a psychiatric hospital from a general hospital if they had been residents of a psychiatric hospital in the past. ACT affords consumers a measure of continuity of care, allowing consumers to receive service from a single team over a period of years. When necessary, hospitalization is brief and focused, and ACTT members maintain contact with consumers who are in hospital. Numerous studies have consistently found that consumers receiving ACTT services are less likely to be hospitalized, and have fewer symptoms and better quality of life than consumers who obtain other types of mental health services.

Research with ACT clients in Ottawa found that consumers liked aspects of ACT services, including home visits, medical care, personalized outings, and the helping relationship with the team. ACT consumers did not like the lack of privacy, limitations in establishing their personal goals, and lack of specific appointment times in their experience as consumers.

The initial application for funding of the ACTT included a plan to have two consumers job share a team position. A single consumer might not receive sufficient support from team colleagues to ensure the success of his/her introduction into the role. The intention was to add two
consumers at a time to the team and test out the optimum mix of professional and consumer team members. This plan was thwarted after the first consumer was hired on a contract. Management and union objections prevented additional hiring of consumers, and resulted in terminating all contract employees at the end of their contracts. Fortunately, all Ontario teams now include at least a half-time consumer member working alongside other team members. While this is inadequate, it is an improvement on past practices.

The inclusion of consumers as full members of the team helps ensure that consumers’ voices are heard and their rights are respected. Experience suggests that the presence of consumers on an ACTT suppresses stereotyping and other negative attitudes common in provider groups. While we support a more equitable mix of consumers and regulated providers on ACTTs, adding even one consumer to the team helps to keep the team more consumer-focused.

Our observation is that the right people with the right dedication can make the worst structure succeed in accomplishing a task. If workers are not client centred or committed to the model of service delivery, they can make the best structure fail. The best model in the wrong hands can fail, and the worst model can succeed when workers are dedicated to helping their clients. ACTTs are no exception to this principle.

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HOUSING ISSUES IN WELLNESS AND RECOVERY IN MENTAL HEALTH

Brian Davidson

Background

In Ontario the role of government policy and funding in the area of housing and mental health has a long and varied history. One of the earliest initiatives for people with serious mental illness was the Approved Homes Program, in which residents remained registered as inpatients at the hospital that referred them. In the 1960s, the Homes for Special Care (HSC) Program began in an attempt to assist Provincial Psychiatric Hospitals with deinstitutionalization and provide patients with opportunities to live in community settings. More recently, Domiciliary Hostels and Habitat Services have added private sector beds to the mental health housing array.

In the 1970s, the non-profit sector was brought into the mental health housing business in a major development known as supportive housing. The most common form of supportive housing has been group or congregate living arrangements, although later projects took the form of apartment settings. A key feature of supportive housing has been the acknowledgement that supports to the clients are a necessary feature and were part of the funding package for individual projects. The idea of a continuum of supports became part of the Ministry’s funding approach, in which levels of support from high to medium to low characterized housing projects. This feature brought the Ministry of Health directly into special needs supportive housing starts initiated through the then Ministry of Housing and in collaboration with financing with the Canada Mortgage and Housing Corporation (CMHC). Through the years of various housing starts, the Ministry of Health attempted to coordinate its community mental health funding with
the Ministry of Housing in order to tie funding to newly acquired stock. The stock or building financing was lead by the Ministry of Housing in the form of mortgage financing and subsidy budget mechanisms for the non-profit groups.

Trainor et al. separate community housing for people with psychiatric disabilities into two overall categories: custodial models and alternative housing models. The former tends to be larger facilities with little or no programming. The latter includes group homes, halfway houses, cooperatives, and supported housing (which features support services that are separate from the housing itself and focuses on helping people live in the “normal” community). Alternative housing programs tend to be fairly small and offer rehabilitative and community support services.

The more recent approach to mental health housing, known as “supported” housing, has gradually become the more common strategy. This approach is characterized by supports that are not strictly tied to the building or house, but tend to be portable. This has occurred for a variety of reasons, including research into consumer preferences and changes to tenancy rights. Often this has been the product of non-profit housing providers' creativity in attempting to stretch their support services to other clients in the community, as well as the growing recognition of the importance of housing by other service providers, such as case managers.

**The Recent Past for MOHLTC**

In 1999, a significant change occurred when the “dedicated” provincial supportive housing portfolio was transferred from the Ministry of Municipal Affairs and Housing (MMAH) to the Ministry of Health and Long-Term Care (MOHLTC). This decision was made in an effort to protect and rationalize supportive housing so that the housing stock would be administered by the same ministry responsible for the support services provided. Most recently another supportive housing portfolio has been transferred. On July 1, 2002, MOHLTC took responsibility for a Federal portfolio of dedicated supportive housing. A Memorandum of Understanding between ministries has been signed which sets out the roles and responsibilities to implement the Federal/Provincial Social Housing Agreement with respect to dedicated supportive housing funded by the Federal Non-Profit Housing Program, the F/P non-profit housing programs, and the provincial non-profit housing programs.

The MOHLTC has now assumed responsibility for the buildings for dedicated supportive housing where it also provides support funding. Centrally, the Supportive Housing Unit of the Mental Health and Addictions Branch has the responsibility for administering this portfolio as it pertains to the bricks and mortar, while the Regional Offices across the province are responsible for the support service funding for supportive and supported housing.

**Mental Health Homelessness Initiative**

On March 23, 1999, the government announced a number of new initiatives to address the immediate and long-term needs of people who are homeless or at risk of becoming homeless. A key part of this announcement was an additional $45 million, in each of the next three years, to develop permanent housing spaces and supports through the MOHLTC for people with a mental illness.

The first phase of the initiative created 962 new supportive housing units in the high need urban centres of Toronto, Ottawa, and Hamilton. This phase targeted people with a serious mental illness who were intensive users of emergency hostels, as demonstrated through longer stays and/ or frequent use. These three cities were targeted for Phase 1, as these municipalities had the highest emergency hostel expenditures. The 962 units include 197 purchased units and 765 head lease units in apartments.

On November 22, 2000, Phase 2 of the initiative allocated a further 2640 units in communities across the province. This allocation included a total of 645 units targeted for capital purchase and renovation and 1995 units targeted for head lease in apartments. Phase 2 targeted all communities in Ontario and addressed the needs of clients who were homeless or at risk of becoming homeless. It specifically targeted persons being discharged from the Provincial Psychiatric Hospitals (PPHs) currently undergoing restructuring and divestment.

In order to ensure that needed support levels were part of the initiative, an overall average staff/client ratio of 1:8 to 1:10, for support services, was used as a guideline in the allocation model. The model also allocated funds for rent supplements based on regional average rents. Estimates of capital purchases were based on average real estate prices, including renovation costs.

The initiative allowed for two possible housing options to secure modest, affordable, and permanent accommodation. The first option involved the transfer payment agency entering into an agreement to rent units from a private or non-profit property owner/landlord. The agreement with the owner/landlord would be to pay the difference in rent between what the tenant would pay and the Ministry-approved market rent for the units. The second option was the direct purchase of a property by the transfer payment agency. The agency would enter into an agreement with MOHLTC which detailed the terms and conditions of the purchase, including Ministry requirements relating to renovation.

Proposals prepared for submission by agencies were requested to demonstrate leveraging potential through partnerships and to ensure the delivery of support services that were consistent with the goals of mental health reform, including utilizing current services in the...
mental health system as back-up to complex client problems (e.g., Assertive Community Treatment Teams).

The initiative was prepared in the form of an Expression of Interest in order to focus the work to be done in a particular fashion. Much of the innovation and resourcefulness in supportive and supported housing has always come from the agencies responsible for managing housing projects. Therefore the idea was to, as much as possible, engage existing supportive housing experts within the Ministry's own portfolio to take the basic model and shape it locally, based on existing availability of apartments and housing stock.

Next Steps

The concept of “recovery” has emerged in Ontario as an important momentum, largely through the efforts of the Mental Health Implementation Task Forces. “Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of psychiatric disability.”

Hatfield and Lefley have alluded to defined recovery in relation to the mental health housing sector in the following statement: “Recovery means a kind of readaptation to illness that allows life to go forward in a meaningful way. The adaptive response is not an end state. It is a process in which the person is continually trying to maximize the fit between his or her needs and the environment.”

As housing has become recognized as an essential need for any person recovering from a mental illness, the fit between his or her needs and the housing situation (a major part of the environment) has become paramount. The essential challenge for the recovery approach in community mental health housing is the history and reliance on models of service and the actual form that housing took over the years, or the inability to implement what best practice identifies as working. Both government and local providers of housing and supports will need to take up the challenge of revisiting historical funding models and the physical forms of that housing. A variety of housing options currently does exist across the province, but not enough to meet the projected need. What does exist within the dedicated supportive housing portfolio could be in part reconceptualized and redesigned to be more in keeping with client preferences for single occupancy and supported housing. It should be noted that the best practice literature does caution against relying solely on supported housing and the potential to underfund the supportive aspect. How many group or congregate living situations are needed or will be the choice of clients is the question to answer at the local level.

From the homelessness initiative several important factors for future housing planning have emerged. For example, in some communities across the province the availability of private market apartments has become a problem. This is due to a number of factors, but primarily the vacancy rate in some communities is so low and all available units have already been acquired. This is not true in all communities, in some larger cities there is still capacity to do more as vacancy rates improve in the private apartment sector and some project sponsors gain increasing expertise in acquiring these units.

Likewise, in the case of acquisition and renovation of existing buildings across the province, many communities lack appropriate existing stock or the available stock has already been acquired through the homelessness initiative or earlier supportive housing starts of the 1970s and 1980s. Again, there are exceptions across the province, for example, in some regions the acquisition and renovation option was not pursued in the homelessness initiative, as the preferred option was private apartments. There may now be interest in this option and available stock across those regions to acquire. In most regions the take up of both private sector apartments and acquisition has generally occurred in larger urban centers, which can mean availability might be possible in some smaller targeted communities.

One of the very positive results of the homelessness initiative is that there now exists in every region a knowledgeable and capable group of housing providers who understand local housing markets and who have intimate knowledge of what capacity exists in local communities. As well, a number of innovations have begun locally to rethink housing portfolios, which may include supportive, supported, and private market units. For example, some current supportive housing clients in group living situations may not need or desire this form of housing and might prefer an apartment made available through the homelessness initiative. This could lead to freeing a space for someone whose current needs or wishes might be met through a group setting.

Overall, the community mental health housing field appears well equipped to take up the challenge to develop more housing options for people with serious mental illness. The large need for more housing across the province will certainly demand more funding, but innovations can occur within existing housing portfolios as well.

3 Agnes B. Hatfield and Harriet P. Lefley. Surviving Mental Illness: Stress, Coping and Adaptation.

* Brian Davidson is Manager, Supportive Housing Unit, Mental Health and Addictions Branch where he is responsible for Supportive Housing and the implementation of Assertive Community Treatment Teams.
When consumer/survivor Linda Chamberlain shared her personal story of how marginalization and a life of hell in decrepit rooming houses changed when she received affordable housing and supports, people sat up and listened. Some were fellow consumers who knew exactly what she had experienced. Some were family members of consumers who had seen their loved ones in similar straits. Others that night were community members who had never heard that message so powerfully delivered. But everyone at that meeting of the Boards for Mental Health and Housing Services knew that here was a message that needed to be carried to politicians, policy makers, and citizens in Toronto and beyond. The Dream Team was thus born to share that message. Dream Team members dream of a province where supportive housing is the first step to recovery. We believe that safe affordable housing is a human right.

The mission of the Dream Team is to advocate for more supportive housing in Ontario by telling their stories about the life-altering benefits of supportive housing to politicians, community groups, and institutions.

Our goals are:

- To promote acceptance by society of marginalized people and those with mental illness.
- To make it possible for marginalized people to achieve the fullest sense of self-worth and participation by ensuring safe, secure, affordable housing and social supports.

Here is an example of the stories we tell. This is my story:

Thirty-three years ago I was a confused and severely depressed teenager setting out on an odyssey in search of community and sanity. I first found help at a community psychiatric clinic where I hoped that I would find relief from the feelings of guilt and isolation which drove me to repeatedly attempt to kill myself. Concerned treatment from some excellent psychiatrists introduced me to all the then current tricyclic antidepressants and later, to most of the recent selective serotonin re-uptake inhibitors. Unfortunately, like a sizable minority of serious chronic depressives, my response to drug therapy was limited. Two series of shock treatments also failed to stabilize my mood. Hospitalization after hospitalization was the result.

In the meantime, I searched for a way to live my life. At times I was less impaired by depression and able to achieve at university and at work. While looking for a “family” of people with shared values I served in leadership positions in my church and my political party. But deeper depression always returned. It impaired my judgment and caused me to disappoint people who counted on me as I disappointed myself. The cycle always ended in self-loathing and further isolation. I couldn’t understand how people could speak of life as a “gift.” That concept seemed like a cruel mockery of my life experience.

It was about six and a half years ago that I learned about supportive housing and Houselink Community Homes. A social worker who was preparing me for discharge from a hospital psychiatric ward suggested supportive housing as a way to live a more secure life. And it has been! For the past six years I have been sharing a gracious house in the Annex with four other Houselink members. It feels like the first real home of my life. I take pride in gardening the flowerbed in the front yard and in keeping my home clean. I’ve volunteered at a local thrift shop. My neighbours greet me by name and ask after my dog, Beau. I feel that I am part of the local community and the community of Houselink. The respect and acceptance that I feel raises my spirits so that I can be more accepting of myself. My depressions don’t seem as deep, so I need hospitalization less frequently.

Because I have stability and support I’m a more resilient woman now. And life is beginning to feel like a gift to me. I’m grateful for this. But every time I think of my safety and comfort I wonder how many others are just beginning their odyssey for sanity and community. I know that supportive housing can be a lifesaver. As a director of Houselink and a psychiatric consumer I want to urge everyone I can speak to to help us provide the housing and support that so many still lack, so that they too can know that life can be a gift.

It is now almost four years since the Dream Team began. The team of about 16 consumers, family members, and community supporters has taken our message to all levels of government, university, and high school classes, conventions, churches, and community groups in Toronto and the Province. We’ve evolved into an empowering, consumer-centred team where the consumer majority works in partnership with others. It’s a challenging dynamic for all involved, but we are confident that the
Dream Team will continue to advocate for the homeless and the inadequately housed consumer and to challenge stereotypes about consumer/survivors.

Susan McMurdo has been a member of the Dream Team for 3 years. She is also on the Board of Houselink Community Homes and lives with her dog "Beau" in the Annex area of Toronto.

ONTARIO'S FORENSIC MENTAL HEALTH SYSTEM: THE NEEDS OF THE MENTALLY DISORDERED OFFENDER

Dennis Helm* and Jim Cyr✝

Introduction
Service needs of the mentally disordered offender have traditionally been viewed as a separate or distinct component of the mental health system. The result has been the marginalization of this population. There continues to be a significant challenge in integrating service needs of this population into the broader mental health and health care system of Ontario. Central to this integration is the role and success of the Psychiatric Patient Advocate Office.

Historical Overview of the Forensic System
The provision of forensic services to mentally disordered offenders (MDOs) is a federally mandated service for which provincial health ministries have historically accepted responsibility. In addition to addressing the mental health needs of offenders, forensic services contribute directly to the safety of the community by reducing the risk posed by the mentally ill offender through effective assessment, treatment, and rehabilitation.

MDOs are a very heterogeneous population from a clinical perspective. Diagnoses include psychoses, personality disorders, acquired brain injuries, and the developmentally handicapped. The term “forensic” is very much a legal label, acquired through involvement with the criminal justice process, where the presence or suspicion of a mental disorder causes an accused person to be directed for psychiatric assessment or treatment.

Legal Context
Currently, Ontario’s forensic mental health system is directed by the Mental Disorder provisions of the Criminal Code of Canada." These provisions spell out a range of options for dealing with an accused person appearing before a court and who has (or is thought to have) a mental disorder.

The two aspects of the recent Mental Disorder Amendments, presenting the greatest challenge to both the health care provider and advocate, are compulsory treatment and the enumerated factors to be considered by the court or Ontario Review Board (ORB) when making a disposition. The factors to be considered by the court or ORB in determining dispositions are:

1) the need to protect the public from dangerous persons;
2) the mental condition of the accused;
3) the reintegration of the accused into society; and
4) the other needs of the accused.

The disposition made must be the least onerous, least intrusive, and least restrictive. In these instances, we are confronted with the concept that the individual’s needs or wishes are not the primary considerations. The concept of making a disposition or providing treatment without the consent of the client raises complex questions. It is also contrary to the Psychiatric Patient Advocate Office’s (PPAO) belief in an individual’s right to self-determination. Both the Ministry of Health and Long-Term Care (MOHLTC) and the PPAO staff have worked together on educational initiatives to ensure the provision of the best service to our clients.

As a result of the Criminal Code amendments, both the MOHLTC and the PPAO have experienced an increased demand for service from the forensic population. The MOHLTC has increased the number of beds designated as forensic and has developed provincial implementation plans. According to the 2001 PPAO Annual Report, of the 2,113 files opened, 35.3% were deemed to be “forensic” and “detained under the Criminal Code of Canada.” This represents an increase of 124 cases since 1999. The PPAO has developed an InfoGuide entitled “Appealing an Ontario Review Board Decision” and the PPAO Patient Advocates are advised of pending appeals in which clients are unrepresented. At that point, the Patient Advocate speaks with the client to ensure the client wishes to proceed without counsel. If the client would like counsel, the Patient Advocate assists in locating a lawyer and applying for Legal Aid.

In addition, the Code specifies that, where detention in custody is necessary to address assessment and treatment requirements, the accused may only be detained in a hospital designated by the Minister of Health and Long-Term Care. The designated hospitals provide services to mentally disordered offenders in the following ways:
From a quality of life point of view, as well as the needs as clients in the general psychiatric population. The majority of forensic clients exhibit the same following:

- Psychiatric Disorders and Related Needs - mental illness, brain injury, substance use disorders, and other health conditions;
- Mental Health Interventions - pharmacological, psychological, and cognitive-behavioral therapies;
- Social Support - family, friends, and community support.

Health services be used only when absolutely necessary.

Five years ago, the majority of forensic beds, it is desirable that specialized inpatient services be used only when absolutely necessary. Significant staff costs associated with operating forensic beds, it is desirable that specialized inpatient services be used only when absolutely necessary. Forensic beds, it is desirable that specialized inpatient services be used only when absolutely necessary.

The Forensic Treatment/Care Approaches

The major areas of required expertise for assessment, treatment, and rehabilitation are:

- **Biological Therapies** – physical and pharmacological therapies;
- **Cognitive Therapies and Knowledge Deficits** – cognitive approaches to risk management;
- **Behaviour Therapies and Skills Acquisition** – behavioural approaches to the treatment of risk factors and/or practical skill acquisition; and
- **Risk Assessment** – use of clinical and situational factors together with actuarial risk factors and/or practical skill acquisition; and

The revisions to these amendments impacted on the provision of service to forensic clients by the PPAO and the MOHLTC. As a result, the PPAO addressed the significant implications to its mandate, operations, staff, and the delivery of advocacy and rights protections services to this population. This proactive stance continues. In 2002, the PPAO provided a written submission to the Standing Committee on Justice and Human Rights on their Issue Paper involving a Review of the Mental Disorder Provisions of the Criminal Code of Canada. During this same period, a number of initiatives to address forensic needs were undertaken by the MOHLTC, not the least of which was the Human Services and Justice Coordination Project and the Range of Forensic Services in Ontario.

The provision of efficient and effective services to ensure that Ontario’s mental health system best meets the needs of all people with serious mental illness is integral to mental health reform. The reformed mental health system includes people, commonly identified as forensic clients, who have multiple and complex overlapping needs relating to aggression, legal status, and clinical/risk management. Due to the nature of these multiple and complex needs, health, social service, and judicial systems continue to be active in helping to shape mental health reform by highlighting issues that need to be addressed from a client-centered and client-first perspective. Advocacy must be considered an essential component of mental health reform and it must be available to all individuals with a mental illness regardless of where or from whom they receive their care and treatment. The PPAO was recently an active player in ensuring that the Mental Health Implementation Task Forces and the Forensic Mental Health Services Expert Advisory Panel considered advocacy as an essential and integral component of mental health reform.

**Ontario’s Forensic Strategy**

The Provincial Forensic System Strategic Directions Report (1997) outlines corporate strategic directions concerning the operation of forensic mental health services, including the vision, goals, and principles that
should guide the provision of services, and the description and role of the key services comprising the provincial forensic system. This document continues to provide the policy/implementation framework for the Ontario system.

**Vision**
A system of care for mentally disordered offenders should be provided where:

1) People will not be stigmatized or discriminated against on account of mental disorder;
2) Mentally disordered offenders will be integrated within broader mental health programs and services, consistent with level of risk and needs;
3) The lives of offenders with a mental disorder can and will improve;
4) Mentally disordered offenders will have a voice in the ways they choose to live, learn, work, and relax – taking into account the need to protect;
5) A comprehensive service delivery system will be established that is accessible to mentally disordered offenders and which is consumer-focused, quality-driven, equitable, respectful of diversity, integrated, and accountable;
6) Community acceptance and tolerance of mentally disordered offenders will be strengthened through active and dynamic public education activities; and
7) The Ministry will cooperate with our partners in the criminal justice, correctional, and social services systems in developing strategies to reduce crime, implement appropriate alternatives to criminal justice prosecution and incarceration, protect public safety, and provide for the welfare and well-being of individual mentally disordered clients.

**Goals**
The goals of a system of care for mentally disordered offenders are:

1) To balance the rehabilitation and reintegration needs of forensic clients with the need to protect public safety;
2) To work within the required legal parameters, and provide for the successful and least restrictive assessment, treatment, rehabilitation, and safe reintegration of clients into their community;
3) To provide resources proportionate to regional needs and priorities, with access to services occurring at the lowest security level and as close to home as possible;
4) To conduct forensic-focused research and provide education; and
5) To communicate effectively and coordinate mental health services with the criminal justice, correctional, and social services systems.

**Principles**
Principles in relation to serving this population include:

1) Treatment, care and support will be accessible, equitable, and developed with consumer and family input;
2) Services will be designed to meet the special needs of mentally disordered offenders, and will be sensitive to gender, culture, and race, etc.;
3) Programs will be quality driven and evidence-based;
4) Legal status must not serve as a barrier to mentally disordered people in accessing clinically appropriate services;
5) Most intensive services will be targeted to individuals of the highest need;
6) Services provided in the system will be flexible, adaptable, and responsive;
7) Services will respect the values and capabilities of families and other support or service networks; and
8) Services will be planned according to the provincial mental health policy framework.

To assist with the effective implementation of a restructured forensic service system, a review of forensic mental health services policy was conducted from March to May 2000. The review included:

- Targeted consultations with key stakeholders;
- A summary of existing interministerial and MOHLTC forensic policy, specific questions addressed, and comments of participants recorded; and
- A review of past Ontario reports and reports of other jurisdictions' experiences with forensic services.

The following issues were identified as requiring MOHLTC attention:

1) Interministerial coordination of forensic services, with focused leadership;
2) The need to consolidate and clarify existing MOHLTC forensic policy; and
3) Processes to improve services for forensic clients.

The following recommendation was made to address the above issues:

- Creation of a time-limited provincial Forensic Mental Health Services Expert Advisory Panel to provide advice on the interministerial coordination and implementation of existing forensic policy.

**Provincial Forensic Mental Health Services Expert Advisory Panel**
The Forensic Mental Health Services Expert Advisory Panel was established in January 2001 by the Minister of Health and Long-Term Care and ended on December 31, 2002, with the submission of a final report to the Minister.

The Forensic Expert Panel identified the following five categories of issues and, based on its review of these issues, made 40 recommendations for the Minister's consideration:
Ontario’s Forensic Mental Health System: The Needs of the Mentally Disordered Offender

1) Leadership and Accountability;
2) Information and Data;
3) Concepts and Definitions;
4) System Capacity and Integration; and
5) Interministerial Issues.

Conclusion

Recent work internal and external to the Ministry has reinforced the direction of Ontario’s implementation strategy and has articulated specific implementation strategies that should be followed. Strategic implementation strategies will continue to be developed.

Central to the success of developing a reformed mental health system and, in particular, the establishment of an effective and integrated provincial forensic system, is “the recognition of advocacy as an essential and integral component of a reformed mental health system”.

Introduction

As the province moves forward with its plans to implement Making It Happen, including shifting or “divesting” the remaining provincial psychiatric hospitals from provincial control to independent governance, significant stress has been placed on our forensic mental health system. Once overseen by the Ministry of Health and Long-Term Care, with central administrative and legal processes in place, the forensic system is now fragmented into individual facilities, each developing its own method of providing forensic care. Without central administrative guidance, regional differences are significant, creating inconsistency and uncertainty of process. Ontario lacks a unified vision for the care and treatment of persons with mental illness who have come into contact with the law.

As new facilities take on the responsibility of forensic beds, new policies are developed, new practices are designed, and the decentralized programs become more and more distinct. The lack of a central body to disseminate best practices, to give direction based on years of corporate memory, and to provide legal support results in vastly different services available depending on region. Patients are left with uncertainty regarding the rules under which they live – and what to expect if they are transferred to a different facility. The changes reportedly create tremendous confusion and disempowerment for patients within facilities.

More disturbing, we have observed in a number of facilities that the changing environment means a move ever closer to a “security” and “punitive” system rather than that of mental health care and treatment. While the provincial forensic mental health system over years of service delivery had developed and implemented an effective balance between safety and care, the new divested facilities have begun the process anew with the stigmatizing assumption that their patients must be “punished.” The tendency to focus on security and public safety to the exclusion of care and treatment has made some of the facilities look more like correctional facilities than hospitals.

The province’s divestment plan requires a unifying body that will ensure that forensic services maintain an emphasis on care, that will provide guidelines, policies and best practices and that will monitor compliance with the law and provincial standards. Failure to ensure such an oversight body was in place prior to divestment has left patients in a remarkably vulnerable position, with shifting rules and practices and no recourse.

Security versus Care: New Policies, New Rules

As each new facility receives forensic beds from the province, administration reviews the policies and

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4) R. S.O. 1992, c. 31 (CTA), repealed by S.O. 1996, c. 2, s. 2.
procedures to ensure that they conform to the broader, corporate vision of the hospital. Critical review is a necessary and commendable effort that helps to ensure that policies are consistent with current best practice information. However, as a patient living day-to-day on a forensic ward, the policy changes can seem ongoing and random. New rules affect daily living and very little information is forthcoming as to why the new rule has been implemented. Simple changes like the unending additions to the number and types of contraband items on wards can lead to feelings of frustration, loss of control, and powerlessness.

Patients have rarely been active participants in developing the new environments and feel that they do not have a voice in the systemic changes that are happening around them. Patient Advocates are little better prepared to deal with the changes that result post-divestment. While some facilities have made a significant effort to include Patient Advocates in policy development and implementation, many new administrators are reluctant. As a consequence, Patient Advocates are unable to bring the client-centred policy approach to the table or influence processes that specifically exclude patient concerns and input. In these cases, the Patient Advocates are always providing service in a reactive mode instead of the facility seeing them as a resource and allowing them to participate using a more proactive approach.

Fundamental systemic changes are also demonstrable in the fluctuating definitions of security levels. Traditional understanding of the privilege levels associated with minimum, medium, and maximum secure units no longer define current practice. Some “minimum” secure settings in divested facilities have incorporated elements from much harsher clinical settings – sally ports, routine ward searches, and visitor restrictions – while other facilities maintain the minimum secure protocols. Patients being transferred between facilities are left baffled by the changing rules and uncertain whether a move will lead to greater freedom.

**Stigma**

Not only has there been tremendous change in the forensic system, but much of that change has signaled a fundamental shift in the philosophy of forensic care and treatment. The *Criminal Code of Canada*\(^3\) allows for persons who are either unfit to stand trial or those who have been found not criminally responsible on account of mental disorder\(^4\) to be shifted from the criminal justice system into mental health care and treatment. In part, the shift recognizes that such persons have not been convicted of offences and further, that they are incapable of having formed the intent to break the law.\(^5\) Accordingly, such persons are made “patients” within the mental health system rather than “inmates” in jails.

However, as more facilities divest from provincial control, forensic patients are dealt with more often as criminals. Drastic policy changes that penalize patients are justified as “security” precautions. Patients are punished for having had mental illness and for their involvement with the justice system.

What has been lost in the system is a basic understanding of forensic patients. Not only are these individuals not convicted of crimes because of their illness, but the vast majority have been involved in relatively minor offences which have not involved injury to others. Many of those within the forensic population have been involved in incidents similar to those involving patients in the civil system. While one individual may have been arrested and charged with a minor criminal offence for particular behaviour, another may have been diverted from the criminal system and received care civilly as a result of the same actions. A third person may not have come into contact with the law at all as their support network allowed them to access other services. Some have only been charged after they have arrived in the civil system when health care practitioners criminalize their behaviour and lay charges within facilities.

Persons with mental illness are often diverted into the forensic system intentionally, not because of particular behaviours or symptoms, but because of an impression often held by well-meaning family, service providers, and criminal lawyers that the forensic system offers the “gold standard” of mental health care and treatment. Diverting an individual into the forensic system is often seen as a means to access care and treatment that is otherwise in short supply in many communities.

Despite the fact that most forensic patients are similar in illness, symptoms, and behaviour to persons civilly committed, divested forensic wards create policies that mirror “punishment” models from jails. Repeatedly, when asking about the advent of a policy, Patient Advocates are told by hospital staff that the patients have committed crimes; that part of the hospital role is “custody”; and that to adequately protect the public certain security measures must be instituted. The balance between public safety and security and treatment has been tipped towards a more restricted and punitive environment that is not conducive to wellness or recovery. Rather than decreasing the stigma attached to mental illness and involvement with the criminal justice system, divested forensic facilities seem to reinforce and deepen the misconceptions.

It has left some patients and Patient Advocates wondering if recovery in the forensic mental health system is even possible and whether community reintegration is possible. Patients are faced with the troubling dual role of their health care workers – nurses and doctors who provide care and treatment are the same persons responsible for calling the police to lay charges and to collect information to be used against a patient at yearly Ontario Review Board hearings. Ward policies reflect the need to “punish” patients for their index offences. Community reintegration starts with broad disclosures of index offences and risk assessments. A public already wary of
persons with “mental illness” responds to the reactions of hospitals and hospital staff — the constant reiteration of dangerousness and safety concerns further feeds misperceptions, making reintegration more difficult. The patient is left trying to return to a community with the constant reminder of his or her criminality.

**Loss of Complaint Mechanism**

Despite the concerns raised by patients and received by Patient Advocates, rarely will complaints proceed to a process of resolution. Without funding to bring court actions forcing facilities to comply with legislation and the *Charter of Rights and Freedoms* for matters such as improper searches, patients have little recourse when their rights are violated. Patients believe that complaints to colleges are meaningless, as only the most minimal lip service is paid to persons with mental illness. The Ministry does not presently police its own legislation to ensure facilities and staff comply with the law and attempts to lay charges through the police or justices of the peace under the *Mental Health Act* have been sporadic and, so far, unsuccessful.

Patients in divested facilities no longer have access to the Ombudsman’s investigative and complaint resolution process. Internal dispute resolution is unsatisfying for patients, as it is often not independent of the treatment team.

Persons with mental illness no longer have a voice in the divested system, either in the development of new environments or in the ability to raise concerns. In a client-centred system, patients must have a voice in the development of their care and treatment. Patients must be an integral voice in policy changes and must be able to complain about the care and treatment they receive.

The lack of a transparent, effective complaint mechanism also affects the Patient Advocates’ ability to respond to client concerns. When raising issues internally, the concern that policies are not reflective of provincial standards has little merit with the individual facilities that are creating their own way. Concerns over the legality of certain actions go unanswered when there is no dedicated legal counsel to review the issues raised: the distance between the law and daily practice can only broaden. All too often the facilities are concerned about mitigating risk and liability and are less concerned about the impact on clients, client-centred care, and providing quality mental health services to those in their care. The minimal likelihood that a patient would have the resources to pursue legal action for rights violations will almost always shift “risk” assessments to other areas.

Central to the forensic system concerns is the need for accountability. The Ministry of Health and Long-Term Care has an absolute responsibility to ensure that the law it has created is followed and to ensure that the facilities and health care staff it funds comply with fundamental provincial values of mental health care. While significant ongoing education of facilities, administration, and staff is required, so too is an effective mechanism for reviewing complaints, resolving individual concerns, and creating complaint-based changes where appropriate.

**Conclusion**

The move to divest forensic beds to individual hospitals has advantages, the clearest being that patients will be able to receive care closer to their home communities. Proximity may allow for better recovery and reintegration into the community, as patients can maintain family, friends, and other supportive relationships. Community access can occur in a setting in which the patient is familiar and comfortable.

To date, however, the purported advantages of the divestment process have been vastly overshadowed in the forensic system by the haphazard implementation process, the rapid and inconsistent changes throughout the province, and the heightened stigma attached to being a “forensic patient.” The province must take steps to ensure that there is a philosophy of forensic mental health care developed which will be a measure for all policies that follow. A responsive, patient-centred approach to the forensic system requires a strong, central administration to ensure consistency throughout the province, best practice development, and effective complaint resolution.

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2. The authors acknowledge that an expert forensic panel had been appointed by the provincial government to identify concerns and make recommendations. At the time of writing the report had not been released.
4. Ibid., Part XX.1.
5. In the case of persons found not criminally responsible on account of mental disorder.
8. Section 80 of the *Mental Health Act* creates a provincial offence where persons breaching the legislation may be fined up to $25,000.

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ADULT SURVIVORS OF CHILDHOOD TRAUMA: THE NEED FOR SAFETY AND APPROPRIATELY MODULATED TREATMENT WHILE IN PSYCHIATRIC HOSPITALS

Barbara Everett

Introduction

There is now a growing understanding that there is a link between histories of childhood trauma and mental illness. Research has shown that as many as 70% of outpatients and 72% of inpatients with serious mental illness have histories of abuse. In a survey of hundreds of Canadian psychiatric nurses and nursing assistants, 50% of respondents felt they didn't have the skills to help survivors of abuse, 65% acknowledged limited ability to discuss abuse with clients, and 80% were unsure how to plan treatments that would be helpful.

The signs, symptoms and behaviours associated with a history of childhood trauma are well documented in the literature. Further, treatment methodologies have been researched extensively and have shown themselves to be effective.

Given the known prevalence of abuse histories among people with serious mental illness, it can be argued that they have the right to have their childhood experiences taken into account when they are admitted to a psychiatric hospital, first, so that they may be kept safe from further harm, and so that they may have access to appropriate and effectively modulated treatment.

Asking About an Abuse History

In order to begin to be helpful to people with histories of childhood trauma, professionals must know about their experiences. However, it is not as straightforward as mandating a question about childhood trauma on intake assessment forms.

Professionals must first ask themselves some important questions:

1. Is this the right moment to ask? Do I have time to listen? Is the client sufficiently stable to make a disclosure?

2. Clients have the right to know the point of making this sort of disclosure. Can I explain to clients why I am asking? And can I assure clients that the information will be taken into account when planning treatment, making referrals, and keeping them safe while in hospital?

3. Do I have the skills to listen to disclosures in a respectful but neutral manner and do I know how to deal with the aftermath of disclosure?

4. Am I aware of and able to communicate to clients the limits of confidentiality?

5. Have I offered clients the right not to answer my questions regarding their history of abuse?

Disclosing abuse is not a routine event and carries with it potential consequences both for clients and for the listening professional. Disclosure can be highly emotional and clients may feel that they are about to lose control – either moving back into psychosis, becoming uncontrollably angry, or initiating an episode of self-harm. For professionals, hearing stories of horrific abuse can be damaging to their own mental health if they are unprepared. Secondary trauma and vicarious traumatization can be the debilitating results of repeated exposure to clients’ stories of childhood trauma. Thus, while clients have the right to have their histories known so that treatment plans can be as effective as possible, the process by which this information comes to the attention of professionals must be skillfully and delicately handled.

The Need for Safety

Research has shown that survivors of childhood trauma are more likely to be physically or sexually assaulted in adulthood, with the risk of rape, battering and sexual harassment double for women who have a history of abuse. Sometimes, this violence is inwardly directed, meaning that self-harm and suicide attempts are common. In addition, survivors often lead unstable lives due to poor living conditions, violent interpersonal relationships, involvement in the sex trades, drug or alcohol abuse, homelessness, and incarceration in institutions – all of which places them at risk of further harm.

All patients have a right to be kept safe while in hospital. However, survivors of abuse, having experienced repeated and often violent incursions upon their physical, sexual and emotional boundaries in childhood, are particularly vulnerable. Trauma re-enactment syndrome is a feature of how survivors interact with the world. These patterns of revictimization are hard for others to understand because, intuitively, we expect that people who have such painful pasts would avoid any circumstance that may expose them to further danger. Not so. Survivors have learned to survive abuse, not how to stop it or prevent it. As a result, they are prone to putting themselves in harm’s way over and over again, trying, at an unconscious level, to relive the original assaults – but this time, escaping, getting revenge or successfully defending themselves. Because of their pasts, they do not have the same alarm bells that others do. When threatened, previous tactics automatically kick in, rendering them more, rather than less, vulnerable. They may space out (dissociate), become numb or retreat into psychosis as a way to get through the assault.

Trauma re-enactment syndrome is activated in survivors particularly in inpatient psychiatric settings where there are multiple sources of danger – a general ward atmosphere of tension, a need to confront or engage with staff on power issues, the calling of codes when actual
assaults occur, high levels of noise, dressing in pajamas (in the course of living on the ward), sleeping in an unlocked room, showering or bathing conditions, the presence of men (for women and men abused by men), the presence of women (for women and men abused by women), the use of seclusion or mechanical restraint, and medication by injection during acting out episodes.

While it must be forthrightly acknowledged that psychiatric wards are difficult places, there are steps, focused on the safety of both staff and patients, that can be taken. Staff can develop strategies for handling episodes of self-harm in a positive, non-punitive manner. A code of conduct can be developed by patients themselves and posted prominently, but it must also be fairly enforced. Survivors regress in the face of inconsistency, often called splitting, meaning that one part of the team sees the survivor as a victim expressing his or her pain, while another part sees him or her as demanding and manipulative. Inpatient teams must work extremely hard at developing agreed-upon treatment plans that they then implement in a consistent manner.

Gender-separate wards are a rarity, given the severe pressure on inpatient beds, but on-ward therapeutic groups may benefit from a men-only or women-only approach. Safe rooms could be considered where people could take a time-out, or when patients are psychotic in ways that involve inappropriate sexual behaviour that risks assault or abuse. Discharge plans should ensure that housing and support referrals to community resources take the survivor’s history into account. In fact, safety can be addressed in a myriad of ways, both for staff and patients, but primarily, it is the language and culture of safety that needs validation, adoption and constant vigilance.

The Need for Effective Treatment

There is a general concern regarding extensive treatment for abuse while survivors are inpatients because the length of stay may not be long enough to engage in treatment and because the safety measures discussed above may not be in place. In addition, during the healing process, survivors require considerable support beyond the therapeutic encounter – support that is most effectively supplied by friends, family and professionals such as case managers or housing workers. These supports are less readily available when survivors are in hospital.

However, it is entirely appropriate for inpatient teams to devise “containment” strategies for survivors.10 These strategies ensure that an abusive past is validated but avoid therapies designed to uncover the wounds. For example, psychoeducational groups teach subjects like self-care, relationship skills, assertiveness or the basics of anger management in a school-like atmosphere whereby survivors are engaged on an intellectual, rather than emotional, level.

Eye movement desensitization and reprocessing (EMDR) is a particular (although not widely available) treatment that can be practiced in a way that limits invasiveness and yet can relieve anxiety.11 EMDR is a treatment that involves eye movement exercises thought to help survivors alleviate symptoms related to the trauma they have suffered (flashbacks, the deep pain of remembering, emotional overwhelm, spacing out and so on). EMDR is a complicated subject and exactly why it works is hotly debated, but, for the purposes of this brief discussion, the exercises are believed to help survivors re-store traumatic memories in ways that associate them with validating messages – “It wasn’t your fault.” – “You did the best you could to defend yourself.” – messages that are emotionally soothing and validating. EMDR has the potential to work in an inpatient environment because, during the initial stage, it introduces survivors to positive memories and teaches them how to access these warm moments as a self-soothing technique. Second, it can be modulated, meaning that survivors can work on memories of past events that are the least emotionally disturbing, yet still find a measure of relief from troubling symptoms. And third, it works and survivors, above all else, want to lessen their pain.

Conclusion

Advocacy for survivors of abuse who also have a mental illness needs to concentrate on creating a heightened awareness of how their experiences create their present pattern of symptoms and behaviours. It also needs to openly name the sources of violence and trauma that exist in inpatient psychiatric settings and work with staff and patients to devise effective strategies intended to keep everyone safe. Finally, the limitations of what can and cannot be accomplished with survivors while they are inpatients needs to be acknowledged and, within those limits, useful containment methods that have the potential of providing at least a measure of relief should be implemented.

DUAL DIAGNOSIS

S. Morris *

In addition to the high prevalence of mental health issues, individuals with developmental disabilities have an increased prevalence of comorbid disabilities and disorders, including hearing, vision, motor impairments, seizures, and other medical and communication difficulties. The resulting need for health care services is demonstrated by the results of a study in the Netherlands. Individuals with mental retardation comprised 8.1% of the total health care costs in that country, greater than any other diagnostic group, such as those with schizophrenia, alcohol and drug use and heart disease, due in part to all the comorbidities.4

Life-long communication and cognitive disabilities impact negatively on people with developmental disabilities in Ontario and their efforts to access and maintain good health.

The experience reported by clients, families and service providers today is that individuals with a dual diagnosis have frequent contacts with numerous providers, experience health disorders that often remain undiagnosed, and are the recipients of uncoordinated services.5 For example, health disorders (such as an earache or abscessed tooth) are often attributed to a behaviour disturbance (e.g., self-injurious behaviour) and therefore mistakenly associated with developmental disability. Behavioural expressions of depression such as change in sleep pattern or withdrawal from activities are often missed, therefore left undiagnosed, whereas psychosis is often overdiagnosed and as a consequence, people with developmental disabilities are overmedicated.

Historical Review of Dual Diagnosis in Ontario

The Ontario government policy of deinstitutionalization, adopted in 1973, and the Developmental Services Act (1974) shifted the responsibility for individuals with developmental disabilities from the jurisdiction of health to community and social services. This reflected the broader normalization and deinstitutionalization movements that were being led by parent groups in Ontario and around the world and the shift away from an illness service model for individuals with intellectual disabilities. It could be argued that, as a result of this philosophical shift, the quality of life of individuals with a
DUAL DIAGNOSIS

dual diagnosis has been seriously compromised. One reason for this is the closure of 17 institutions operated by MCFCS between 1970 and 2002, which resulted in a significant loss of knowledgeable and skilled professional and support staff. For example, in a 1974 survey across Canada, 74 physicians were found to work full time in institutions for the developmentally disabled. In a similar survey in 2001 it was difficult to find physicians to complete the questionnaire. With the de-emphasis on specialized medical care, inadequate supports now exist to meet the medical needs and psychiatric needs of this vulnerable population.

The Joint Policy Guidelines for the Provision of Services to Persons with a Dual Diagnosis (1997), published by the MOHLTC and MCFCS, provided a much needed framework to support the development of a continuum of community-based supports and services within and across the sectors. The Guidelines identified the roles and functions of various components within each sector, including psychiatric and general hospitals and community mental health and developmental service providers.

In a survey conducted by the Ontario Chapter of the National Association of Dual Diagnosis, the affect of the Policy Guidelines were evaluated against targeted outcomes identified by the ministries. Results indicated that the Guidelines influenced the planning of services and supports through initiation of local and/or regional committees and the development of formal links to local planning (District Health Councils) and funding bodies (Regional Ministry offices). Most committees enhanced cross sector linkages by being co-chaired by mental health and developmental sector representatives and including membership from health, social service, education, and sometimes families, forensic and colleges/universities. The majority of committees focused their initial activities on joint training initiatives for front line staff in both sectors and implementation of cross sector service protocols.

Where Are We In 2003?

Services designed specifically for individuals with a dual diagnosis are now more evident in Ontario than they were 30 years ago. Networks of services providing crisis and safe bed resources are developing in a few areas of the province. Multidisciplinary specialized dual diagnosis consultation and treatment teams based on integrated mental health and developmental approaches are available in some regions. Generic mental health and developmental services are increasingly providing treatment, case management, housing and day program supports to individuals with a dual diagnosis. MCFCS funding has also recognized the need to invest in individualized approaches, particularly for those leaving the school system.

Current Challenges

We are now also dealing with a different agenda than 30 years ago. Cost savings and measurement of outcomes are more emphasized in current policies, as are issues of improved access and recovery. The focus of the MOHLTC mental health reform policies is on those with serious mental illness. Dual Diagnosis is specifically included in this category, however, some mental health providers continue to exclude these individuals for reasons that include lack of a diagnosis, knowledge and/or skill gaps. MCFCS Making Services Work for People policy (1997) does not refer to individuals with a dual diagnosis. It focuses services on those most in need, therefore limiting investment in health promotion and prevention supports for a very vulnerable population. Families today are the majority of primary caregivers and consistently report difficulties in accessing the supports that they need when they need them. Long waiting lists (years) in the developmental sector for community-based housing, day and case management supports exist. Staffing of specialized dual diagnosis resources and the developmental sector remains a significant challenge due to serious gaps in formal training and education, lack of a career path for the field and low salary levels. Individuals with a dual diagnosis remain one of the most marginalized groups in our community today.

Summary

There is certainly greater understanding of the required components of the continuum of supports and services today than 30 years ago. There is also stronger recognition that best practice approaches include a continuum of flexible services across the sectors with access to specialist services and supports. However, we have made only limited progress in ensuring access to services in either or both the mental health and developmental services sectors as outlined in the Interministerial Guidelines (1997). To achieve the vision established for Ontario, policy makers, funders and service providers must:

1) Adopt a lifespan approach to planning and service development, with particular attention to the vulnerable transition period of the child to adult systems (ages 16-30). This would occur through (adapted from Dart et al. and King & Barnett):

- interministerial structures that are committed to support the implementation of locally accessible best practice approaches;
- a community-based habilitative support system with the capacity to provide varying degrees of support over lifetimes in recognition of fluctuating needs, relapsing and/or recurrent psychiatric disorders. This would include specialized housing and day programs for those with more challenging needs such as those with Prader-Willi syndrome, autism or offending behaviours;
• intensive case management (with lower case loads);
• community-based specialized multi-disciplinary consultation and treatment teams; and
• dedicated beds within the continuum of community to general and psychiatric hospital services to ensure specialized supports and safety for individuals with more challenging needs.

2) Recognize the specialist health and service needs of persons returning to their community and accumulate an understanding of the process of de-institutionalization that began in the 1970s and has continued to the present day. Generally, the stories have focussed on the woefully inadequate resources that were set up in communities to deal with the needs of people returning to their community and coping with mental illness.

But it can also be argued that the process of de-institutionalization is more apparent than real. What has occurred is not so much a movement of people from institutional to community settings but rather, for a significant number of men, women and children, a movement from one institution to another - specifically from mental health facility to prison.

Evidence from mental health organizations and our own experience working with people in provincial correctional facilities seems to confirm the figure noted in the Provincial Auditor’s report

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### CONDITIONS IN ONTARIO PROVINCIAL PRISONS:
### A TROUBLING PICTURE

Paula Osmok *

Much has been written about the deinstitutionalization of the mentally ill that began in the 1970s and has continued to the present day. Generally, the stories have focused on the woefully inadequate resources that were set up in communities to deal with the needs of people returning to their community and coping with mental illness.

But it can also be argued that the process of deinstitutionalization is more apparent than real. What has occurred is not so much a movement of people from institutional to community settings but rather, for a significant number of men, women and children, a movement from one institution to another - specifically from mental health facility to prison.

Evidence from mental health organizations and our own experience working with people in provincial correctional facilities seems to confirm the figure noted in the Provincial Auditor’s report of the proportion of inmates in provincial prisons with mental health problems (15% - 20%). Research suggests that individuals with mental health disorders are more vulnerable to arrest and detection for nuisance offences, more likely to be remanded into custody for these minor offences and spend more time on remand and awaiting a sentencing disposition.

With what we know about the effect of pre-trial detention on sentencing, it would stand to reason that mentally disordered individuals are also more likely to be given a sentence of imprisonment. Also, given what we know about the treatment of other disadvantaged groups, they would be less likely to be granted conditional release.

The John Howard Society of Ontario would suggest that there are a number of reasons for this. The social and economic barriers of the mentally ill disadvantage them at all stages in the criminal justice process. Swelling numbers and greater visibility in the community of those who exhibit behaviour that is either a nuisance or ‘scary’

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has led to less tolerance and less understanding. Combine this with unfair stereotypes of the mentally ill, particularly of their risk of violence towards others, and the pressure to get them off our streets seems inevitable. With appropriate alternatives in short supply or, in some areas, non-existent, either through community care or psychiatric facilities, criminal justice solutions become the only way to manage the problem.

The Society believes, and it would appear that both Ontario's Provincial Auditor and Provincial Ombudsman share this view, that mentally disordered individuals are being treated unfairly, especially with respect to the use of imprisonment. Treatment is extremely limited and correctional staff are not trained to handle inmates with mental disorders. Furthermore, prisons are often not equipped to provide even the basics of decent accommodation, never mind meet any special needs of already vulnerable inmates. Being exposed to lengthy lockdowns, lack of recreation, overcrowding, violence, non-smoking, high stress and serious health risks can only exacerbate mental health issues. The undue reliance on criminal justice solutions, particularly the use of imprisonment, to deal with mental health problems is ineffective, unjust and inhumane.

Conditions in provincial prisons were the key concern of the Ontario Ombudsman as he presented his annual report for the 2001-2002 year. The job of the Ontario Ombudsman is to investigate complaints about provincial government organizations. During the year 2001/02, the Ombudsman's office received 21,186 complaints and inquiries. Those from inmates in provincial correctional facilities comprised the largest percentage - 36% of total complaints. The 7,697 complaints received about corrections far exceeded any others, followed next by the Family Responsibility Office about which the Ombudsman received 1,135 complaints. Case examples described in the report relating to the (then) Ministry of Correctional Services included ones such as this:

[A] mentally ill, hearing-impaired young woman, heard screaming and yelling through the heavy doors of the segregation cell where she was held for most of the two months she spent in prison, and lacking regular access to showers and daily fresh air, as required by Ministry policy.

Working to change this scenario demands first an acceptance of the principle of restraint in the use of the criminal law and its powers, particularly that of imprisonment. Currently, however, government rhetoric and action seems to reflect the opposite. The John Howard Society of Ontario believes that no significant action with respect to reducing the needless and inappropriate incarceration of mentally disordered individuals will happen unless the government and its ministries operate on the basis of the principle of restraint. As well, significant change cannot happen through actions instituted by the Corrections Division of the Ministry of Public Safety and Security (MPSS) alone. For example, the police, who are often accepted as being the 'gatekeepers' of the criminal justice system, are often the first encounter that mentally disordered individuals have with the system. These individuals end up in prisons because of decisions made first by the police. Sometimes, people end up in prison because the alternatives for diversion are not pursued by either the police or the Crown Attorney.

And, as with any suspects deemed to be vulnerable, the mentally ill face increased disadvantage, not only because of their increased propensity to answer questions, but often the evidence they do provide may be unreliable or substantially incorrect and may later be used to incriminate them. Changes in this regard require the involvement of the Ministry of Attorney General and the Policing Services Division of the MPSS to ensure that:

- Police are supported in their decisions to use alternatives to the laying of a charge (through guidelines for the use of police discretion not to charge, and through training and evaluation);
- Crown Attorneys are supported in their decisions to divert minor offenders (through guidelines, a screening process and provision of alternatives to the formal court process);
- there is greater consideration of the use of specialized courts for the mentally-disordered accused, and,
- bail conditions are set appropriately and alternatives to pre-trial detention are developed.

Our provincial government, as most are aware, has embarked on what is called an 'Infrastructure Renewal Project'. This includes closing many of the smaller community jails and building of three large mega-jails. Remanded prisoners will be detained at even greater distances from the location of the alleged crime, legal representation, family and other supports. The effects of being remanded in custody can be severe. Many individuals lose their jobs, experience increased health problems, endure relationship stress, and most disturbing, experience higher rates of suicide than sentenced prisoners.

Unlike health care and education, there has been little public debate about the long-term wisdom of the course set for corrections by the current provincial government. Where our correctional system is headed, however, should be a concern for all Ontarians. The changes implemented and proposed reflect a clear direction that relies on harsher sentences and prison environments to deter crime, and continues to promote the primacy of incarceration as a means of achieving public protection. If we want a system that contributes to the reduction of re-offending, is cost effective, treats people fairly and follows basic principles of restraint in the use of incarceration, then we need to take a very serious look at the direction in which our system is headed.
The John Howard Society of Ontario supports the recommendation of the Provincial Auditor regarding the need for the Ministry to expedite efforts to deal with mentally disordered prisoners. In furtherance of this objective, we specifically propose that the Ministry ensure that:

- Community mental health professionals are involved in case management in the prisons and are integral to the process of developing plans for release with those on remand as well as those sentenced;
- an assessment process is in place to identify mentally disordered inmates upon admission and, where a placement in a psychiatric facility is warranted, the transfer takes place as quickly as possible;
- there is greater use of conditional release mechanisms to support the use of community care programs;
- there is ongoing feedback to the Ministry of the Attorney General and the Policing Services Division of the Ministry of Public Safety and Security about the trends with respect to mentally disordered inmates, and ongoing inter-ministerial dialogue about strategies to reduce their numbers; and,
- there is an over-arching plan and targets for reducing the number of minor offenders in prison who could safely and more effectively be managed in the community.

One last point seems almost too obvious to state: there will be limited success in reducing the numbers of mentally disordered individuals in prison if the mental health resources and other support services, such as housing and welfare assistance, do not exist, or are inadequate. The government must make the necessary investments in these areas. A prison, no matter what programs it offers, is not a therapeutic environment.

The Society maintains the important principle that the sentence is, in and of itself, the punishment, and that a person should not be further punished by the conditions of their incarceration or their treatment at the hands of the criminal justice system. It is discouraging indeed that international standards adopted by the United Nations, and officially endorsed by a number of countries - including Canada - are being violated or ignored. As a province of Canada, Ontario shares in these commitments and, therefore, has an obligation to ensure that its policies and practices comply with the UN. These include basic principles that address discrimination, treatment of unconvicted prisoners and prison conditions. Even with improvements in these areas, alternatives to incarceration, including community treatment of mentally ill offenders, offer the best means to protect everyone’s interests.

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4 Ibid.
9 The Standard Minimum Rules for the Treatment of Prisoners was adopted by the United Nations in 1955 and officially endorsed by Canada in 1975.

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MENTAL HEALTH AND AGING

Deana Johnson *

Introduction

Statistics Canada reports that 12% of the population in 1996 were over the age of 65. This is expected to rise to 25% by 2021.1

The 85+ group is the fastest growing segment of the population, therefore, many seniors may live with activity limitations for more than 20 years. As the population ages, the need for mental health services for older adults will increase.

There will be a need for a continuum of services, from community based to institutional, including services to seniors in good mental health, through outreach and preventative education programs.

Substance abuse and misuse, gambling addictions, ethnic and racial diversity, and the abuse and neglect of older adults are added variables that must be addressed. The larger number and greater diversity will present an important challenge to the design and delivery of mental health services to this specialized population.

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120TH ANNIVERSARY SPECIAL REPORT (MAY 2003)
Overview of Mental Health Issues

The major mental health problems facing older adults include anxiety disorders, depression and dementias, such as Alzheimer’s Disease. The complexity of needs (psychiatric, medical, and social) requires specialized mental health services. Some mental illnesses are unique to seniors, e.g., types of dementia, while others are complicated by pre-existing conditions or co-existing problems.

Depression is not a normal part of aging. It is a treatable medical illness which may be a relapse of an earlier depression or triggered by other illnesses, hospitalization, or specific stressors, such as loss or grief. Most older adults are able to adapt and maintain health. Some are, however, unable to maintain a sense of balance when confronted by feelings of persistent grief. Losses could include spouse, friends, job, home, mobility, sensory changes, and health.

Serious illness is the most common cause of depression in the elderly, affecting about 25% of those with chronic illness and as many as 50% of long-term care (LTC) residents, according to the American Association for Geriatric Psychiatry. Serious depression among the elderly can lead to a vicious cycle if not detected and treated: it can cause other illnesses to worsen, leading to deeper depression, which can end in premature death or suicide. Because depression among the elderly occurs within the complexities of various physical, mental, and social problems, it can be difficult to identify. Co-existing medical disorders may also cause some of these symptoms.

Symptoms may include persistent complaints of pain, headaches, fatigue, insomnia, weight loss, and withdrawal from regular activities. Complaints of a lack of energy, unspecified ill feelings and self-neglect (e.g., appearance, eating) are not uncommon. This can be complicated by the difficulty that many seniors have in expressing feelings of depression. The present cohort group of seniors did not grow up when depression was known to be a medical illness, so they fear being seen as “crazy” or having a character weakness. They may think of it as something that they can “snap out of” rather than an illness to be diagnosed and treated by a trained professional.

Alzheimer’s Disease is often associated with severe behaviour management problems. As it progresses, the individual may experience agitation, aggression, difficulty with activities of daily living, insomnia, and wandering. These problems may also be the result of a treatable problem such as pain, infection, or discomfort. This again points to the importance of being able to access specialized geriatric services.

Addictions may be lifelong or late-onset problems. As is the case with depression, stressful life events may exacerbate problems.

Suicide rates among seniors is higher than in other age groups. Studies have found that many have visited a family physician close to the time of suicide, therefore, physicians must be trained to identify the signs and symptoms of depression in the elderly.

Ageism: Why Does it Matter?

Societal values suggest that decline in aging is to be expected and that nothing can be done to improve one’s health once it has begun to deteriorate. This pervasive view can be seen in family members, professionals, and older adults themselves. Expectations affect the vigour with which treatment is sought.

Primary care physicians may have negative attitudes toward the treatment of older people, which undermines the effectiveness and shape of the approach taken. A study by Zylstra and Steitz found that those with the lowest negative biases toward older persons had greater knowledge of late-life depression and were more likely to provide proactive follow-up treatment. Many physicians believe depression is “understandable” or part of normal aging: “What do you expect at your age?” This can lead to inadequate diagnosis and treatment of mental illnesses among the elderly.

Systemic ageism impacts on the priority given to issues affecting older adults and the political will to fund services to address them. In-home counselling services, for example, can be more expensive on the surface but can save future health care dollars that will be needed for costly hospitalizations. It is too easy to be “penny wise and pound foolish.”

Treatment

Standard treatments for mental illnesses among older adults include psychotherapy and pharmacology. But a complete physical is the first step – depression may be a side effect of a medical condition or of medications. Understanding the complexity of problems seen in older adults can help to avoid the cyclical nature of the interactions, i.e., a medical condition leads to mental health/behavioural problems which, if not treated, lead to increased functional disability.

Comprehensive assessment and diagnosis, treatment and management are essential to the mental health of older adults. It is crucial to have access to trained professionals, such as a geriatric psychiatrist, to provide optimal care to this population. A specialized geriatric assessment program can ensure access and continuity of optimum resources and liaison with primary partners. It can also help families understand the illnesses and link them to community supports, where needed. Multidisciplinary teams can help with pooling limited resources and discussing referrals.

Health promotion has been shown to be an effective accompaniment to other psychotherapies. Educating older adults about how to increase control over and improve health in a variety of areas (nutrition, physical activity, alcohol and substance reduction, tobacco use,
stress management) helps maintain their independence and feeling of well-being. Education can also provide a link to appropriate resources.

Other treatments geared toward supporting older adults include peer counselling and “life review” programs.

Peer counselling/self-help programs are generally offered in senior’s centres, where older adults feel safer and more comfortable, and which are more acceptable to them than formal treatment sites. These programs can include telephone reassurance, shopping excursions, friendly visiting, and problem-solving opportunities.

“Life review” activities can help to reframe and integrate life periods and events. A study by Haight et al. found significantly less depression and hopelessness and greater life satisfaction reported following involvement in a “life review” program.

Outreach programs help to keep older adults in the community with “tailor-made” services (e.g., counselling, medication monitoring, visiting nursing), rather than trying to fit a “square peg into a round hole.”

**Access/Barriers to Service**

Some studies suggest that only half of older adults who acknowledge mental health problems receive treatment, and only a fraction receive specialized mental health services. There may be many reasons for this.

1) Older adults may fear the stigma, deny the problem or are reluctant to self-refer.

2) Diagnosis and treatment are often received first by the family physician, who may have inadequate training and may inappropriately prescribe psychotropic medications. Mental illness among older adults is thought, therefore, to be underreported.

3) There may be a failure by professionals to identify signs and symptoms of mental illness in older adults.

4) The physical environment (e.g., heavy doors, uncomfortable chairs, lack of facility for hearing impairments) is not accessible to some older adults.

5) There is a lack of understanding of multiethnic and linguistic issues.

6) There is a lack of coordination between agencies and systems (e.g., mental health, medical, and community seniors organizations).

Work force issues which act as barriers to service include:

- a shortage of mental health professionals trained in aging and aging professionals trained in mental health;
- community mental health organizations lacking staff trained in addressing non-mental health medical needs;
- the shortage of family physicians in some areas, which creates a reliance on clinics and a subsequent loss of continuity;
- the high incidence of mental illness (particularly depression) in long-term care (LTC) facilities, with inadequate treatment available;
- a lack of knowledge and inadequate training of LTC staff about mental health issues;
- difficulty accessing psychiatric services and other mental health professionals in LTC because of limited resources;
- the need to incorporate mental health care as a basic component of LTC; and
- the need for paraprofessional staff/volunteer training, e.g., LTC staff trained and monitored by mental health professionals.

**Conclusion**

Aging baby boomers will put a further strain on an already underserviced area. There are steps that we can and must take to prepare.

1) The Mental Health Service needs for an aging population must start with increasing specialty training programs in geriatric mental health, and integrating aging and mental health content into the curriculum of professional degree programs.

2) Paraprofessionals and volunteers in LTC and senior centres should also be targeted for training, emphasizing the importance of interdisciplinary practice.

3) Encouraging collaboration can help to assure access to a comprehensive range of mental health care.

4) Work must be done, through public education, to change attitudes and behaviour about mental illness and older adults.

5) The involvement of consumers and family, of all ethnicities, by recruiting, training, and employing practitioners knowledgeable about these populations should be encouraged.

By working together across services, systems, and disciplines, creative solutions can be found to help avert the crisis.

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Mental illness, as a label, is not an Aboriginal concept. Tradition teaches us, that people who were experiencing mental or spiritual difficulties were understood and given specialized care dependent upon the circumstance and the severity of their symptoms. Some people, who in Western terms would be classified as mentally ill, were seen as having special powers or as being particularly gifted either spiritually, physically, emotionally, or mentally.

The Aboriginal view of health incorporates three interrelated and interdependent concepts: holistic health, the life cycle and the healing continuum. Being in good health means the mental, physical, emotional, and spiritual needs of an individual are in balance; mental health can be influenced by any one of these components being out of balance. The life cycle explains and provides context for life through the progression of stages: infancy, childhood, youth, adulthood and the senior years. Aboriginal people have individualized health needs that evolve and which must be addressed differently throughout the life cycle. The healing continuum supports Aboriginal self-determination and self-reliance by encouraging the incorporation of health promotion, prevention, treatment, and rehabilitation at the individual, family, and community levels. The health of an individual is addressed holistically within the healing continuum throughout their life cycle. The interdependency of these three concepts reflects the interdependence of individuals, families and communities.

As with other issues, Aboriginal people must have direct input into how mental health services will be delivered. Improved access and effectiveness of mental health programming is only possible when Aboriginal people are involved with all the processes of planning, consultation, delivery, and evaluation as they would pertain to Aboriginal mental health programs and services.

The Ontario Aboriginal Health Advocacy Initiative does not believe the current mental health client care system reflects or meets the mental health needs of the Aboriginal community. For the most part, the mental health services that are available are almost exclusively provided by non-Aboriginal service providers with little understanding of the culture and practices of the people they are intended to serve.

The culturally specific mental health programs that are available have limited coverage and access. The lack of policy and political will to address Aboriginal mental health at both the federal and provincial governmental levels has resulted in the mental health needs of Aboriginal people falling between the jurisdictional cracks and remaining unaddressed. Provincial and federal funding envelopes are often what define mental health programming and structure, rather than community need.

Aboriginal communities lack the participation, resource support, and influence over decision-making that is necessary to ensure appropriate programs and services. Flexibility, not a typical characteristic of mainstream approaches to health, is required to support Aboriginal mental health. The incorporation of traditional healing practices, family involvement, contemporary and traditional medicines are all essential aspects of Aboriginal mental health programming.

There are multiple factors contributing to the poor mental health status of Aboriginal people many of which are rooted in colonization. The process of colonization through the implementation of the Indian Act and early childhood separation from parents to residential schools has resulted in much loss for Aboriginal people: loss of land, traditional lifestyles and language, community social support, and a loss of a shared indigenous identity and meaning in life. This intergenerational trauma which continues to afflict Aboriginal people has manifested itself in inequities in education, employment, incarceration, housing and health.

Many mental health problems can be traced to stem from social and/or economic factors beyond the control of individuals and can be directly related to inter-generational trauma. Psychological distress is described as the difficulty an individual experiences coping with hard life circumstances or as emotional problems with living. Unresolved grief and loss, anxiety disorders, and reactive depression to circumstances of life are just some examples of psychological distress. Aboriginal people figure prominently in the homeless, incarcerated, and substance-abusive populations. These high risk groups make up the majority of mental health consumers and people likely to be diagnosed with psychological distress.

Aboriginal communities everywhere are engaged in what is popularly referred to as a healing movement. The cultural foundations weakened through colonization are...
slowly being restored. As such, Aboriginal people are not simply interested in redirecting public resources but in determining how each aspect of their lives are addressed, including health. Currently, there is much interest in Aboriginal health issues and so, there is much room for partnering if people, communities and governments can develop creative and co-operative methods of working together. Testing the ground for creative partnering is a good means to motivate change, while providing awareness to the issues surrounding Aboriginal mental health. The necessity of creating an effective Aboriginal mental health system should provide the perfect opportunity to step outside the current thinking.

Jessica R.J. Hill, Health Advocacy Developer, Ontario Aboriginal Health Advocacy Initiative.

MULTICULTURALISM AND MENTAL HEALTH IN TORONTO

Caroline Fei-Yeng Kwok *

According to the 2001 Census of Greater Toronto’s 4.6 million people, 1.7 million – or 36.8% – are visible minorities. Indeed, Statistics Canada shows that Toronto leads the way with a higher proportion of immigrants than any other city in the world.¹

The Ontario Mental Health Statistical Sourcebook indicates that one in five Canadians experiences a mental disorder in his or her lifetime.² However, in Toronto, there are only two major ethnoracial mental health centres, namely, Across Boundaries and the Hong Fook Mental Health Association. Across Boundaries is a centre that caters to people of colour, with clients mainly from Africa, the Caribbean, Sri Lanka, South Asia, and the Middle East. The clients at Hong Fook Mental Health Association are Southeast Asians.

Between 2001 and 2002, Across Boundaries had 180 clients.³ Hong Fook Mental Health Association had approximately 317 clients. Does this mean that immigrants do not suffer from mental disorders? Or that they simply do not seek help? Or that the mainstream institutions do not provide appropriate services to them?

As we all know, mental illness is cross-cultural. Clients from these two centres suffer mainly from schizophrenia, depression, bipolar disorders, and post-traumatic disorder.

This article takes a look at some of the factors that might lead to the under-representation of immigrants and people of colour in mental health and to offer possible recommendations.

Causes of Under-representation

1) Social Stigma – Though social stigma towards mental illness exists in mainstream society, the extent of its effect varies within the ethnic communities. This has to do with the different upbringing of the ethnic groups. To the Chinese and Southeast Asians, for example, mental illness is considered a loss of face for the family. Thus, many families tend to hide problems from outsiders, refusing to seek help from mental health programs. The afflicted would delay dealing with the problem unless it became an absolute necessity.

2) Language and Cultural Barriers – Unlike other medical disciplines, psychiatry requires more verbal expression from the clients. Minorities whose native language is not English would feel uncomfortable expressing themselves to a psychiatrist or mental health workers. In early 1990, all the interpreters’ services were closed down in Toronto. This lack of competent interpreters hampers clients from seeking help. As well, people of ethnic backgrounds tend to confine sharing their emotions to their close friends or to their elders. Many have not had any talk therapy sessions in their own countries. Their concept of seeing a doctor would be to have the doctor give them prescriptions as a quick fix. However, this is not the case with psychiatry. Very often, they would drop out during the course of treatment.

3) Lack of Understanding of Mental Illnesses and Mental Health Services – Many immigrants have little knowledge of what mental illness is and little information about the signs of serious mental health problems. As well, the terminology used in Canada may differ from their country. When one is new to Canada, one does not know much about health care services, let alone psychiatric diagnoses. Thus, many are unaware of the health care services that are being offered.

4) Fear of the Mental Health Hospitals – Besides the social stigma issue towards mental health, people of colour may be apprehensive of mental health hospitals. Many come from war-torn areas such as Somalia and Vietnam, where they have been tortured. The mental health hospital would remind them of their unpleasant experiences. Besides, in the mental health hospitals in Toronto, they would have to face nurses and doctors, whom they would view as authority figures, people whom they could neither
trust nor communicate with effectively. In short, they might feel that there were cultural inadequacies in the treatment.

5) **Racism Exists in the Mental Health Institutions** – In the June 1992 Background Paper on Improving Mental Health Supports for Diverse Ethno/Racial Communities in Metro Toronto, it says that “Racism is a major contributor to mental health problems, as well as a barrier to accessing and benefiting from mental health services and supports.”

Racism and discrimination place people of colour at risk for health problems such as depression and anxiety. Their mistrust of mental health services is reinforced by evidence of clinicians’ bias and stereotyping. It is a well-known phenomenon that people of colour face racial discrimination, rejection, and unequal treatment in Toronto. The Surgeon General Report on Mental Health: Culture, Race and Ethnicity (2001): A Supplement to the Surgeon General Report on Mental Health (1999) in the United States points out that “Clinical environments that do not respect, or are incompatible with, the cultures of the people they serve may deter minorities from using services and receiving appropriate care.”

Thus, a person of colour who is mentally ill might not want to seek help from mental health institutions for fear of being discriminated against.

6) **Fear of Not Getting a Job or Housing, and Fear of Repatriation** – Many immigrants come to Canada with the hope of finding a job. With the social stigma towards mental illness and the scarcity of jobs in Toronto, many immigrants would prefer not to disclose their mental health problems to their prospective employers. Many fear that disclosure of their mental health problems might lead them to be expelled from their housing units. As for many refugees, they fear that such disclosures might lead to repatriation.

Having discussed the factors that might lead to the unwillingness of people of colour to seek help in the mental health system, let us now look at some recommendations that would enable mainstream mental health care to better provide services to meet their needs.

1) **Provide Education Programs to Ethnic Minorities about Mental Illness** – Both Across Boundaries and Hong Fook Mental Health Association have provided education programs to their clients. But they should be carried out on a larger scale to educate the general public in order to eradicate social stigma. Mainstream hospitals could initiate more appropriate education programs that are sensitive to the needs of people of colour and are built on community strengths such as spirituality.

2) **Develop Cultural Competence and Anti-Racist Skills for Service Providers** – According to Dr. Stanley Sue, “cultural competence (along with the broader concept of multiculturalism) is the belief that we should not only appreciate and recognize other cultural groups but also be able to effectively work with them.”

In order to achieve this goal, we must train providers to deliver better services, which cater to the needs of the ethnoracial populations. For instance, in the assessment procedure, we must find tests that are linguistically understood by clients. We should also develop cultural competency in services and train service providers on issues such as understanding the cultural and linguistic backgrounds of the clients. Education materials and anti-racism training should be made available to service providers.

3) **Recognition of Foreign-Trained Psychiatrists and Health Care Workers** – In Toronto, there is a lack of well-qualified community psychiatrists who belong to different community of colour groups. According to the Statistics Canada 2001 Census, the Chinese are Canada’s largest visible minority group, with many living in the Greater Toronto Area. However, there are only five Chinese-speaking community psychiatrists and one Vietnamese-speaking psychiatrist in the city. This disparity between the cultural groups and its psychiatrists also exists within other ethnoracial groups. The Ministry of Health should recognize the qualifications and the experiences of foreign-trained psychiatrists in order to meet the needs of the clients.

4) **Provide Funding for Research and Programs** – The Ministry of Health should provide funding for community-based research in order to provide guidelines for programs to be implemented in the Canadian context. Funding should also be provided for programs (including prevention, support, and recovery) that are culturally catered to the needs of the clients and aimed at mental health professionals, administrators, residents, and psychiatrists.

5) **Encourage Advocacy Among the Clients** – Leadership training programs and workshops should be encouraged. Across Boundaries has started its Leadership Training Program for consumers/survivors. Hong Fook Mental Health has its Women’s Leadership Project. But projects like these should be extended on a larger scale with more funding from the Government.

6) **Reinstatement of the Interpreters’ Services** – It is of utmost importance to have the interpreters’ services reinstated, due to the large influx of ethnic minorities. This would allow those with a language barrier more access to mental health services.

7) **Reduce Barriers to Mental Health Care** – One must build trust in mental health services based on
effective treatments and assessments and make them available to ethnoracial minorities. Mental health care services should try to overcome shame, stigma, and discrimination towards mental illness by giving workshops and through media to their clients and families.

In 2003, Toronto’s mainstream mental health organizations seem to be moving toward the direction of improving accessibility of mental health services to ethnic communities. Some efforts are the Toronto-Peel Mental Health Implementation Task Force and the Diversity Program of the Center for Addiction and Mental Health. However, to what extent the Government of Ontario is going to support the already established ethnoracial mental health organizations,

CHILD ADVOCACY: DRAWING THE LINE IN THE SAND

Judy Finlay*

Introduction

Formalized child advocacy has been in place in the province of Ontario since 1982, with the introduction of the Office of the Child and Family Service Advocacy (Advocacy Office) through Section 102 of the Child and Family Service Act. With a history that spans three decades, this is a welcome opportunity to reflect on the critical lessons learned about advocacy in general, and child advocacy in particular. It is important to understand how these lessons propelled us forward in the work that we do today.

The role of the Advocacy Office is threefold. First, and most importantly, it is to elevate the voice of youth. This means more than empowering youth to speak out on their own behalf. It means more than faithfully replaying their words. The standard to which we aspire is articulated in an African proverb: “Don’t speak about us, without us.” It means speaking together with youth about youth. Second, the role of the Advocacy Office is to intervene when children who live outside of their family’s care report abuse or harsh treatment. Third, it is to ensure that care providers respect the legislated rights and entitlements of children and youth in Ontario.

Lessons Learned

- Advocacy is not a skill, nor is it an intervention strategy or practice tool. Advocacy is a lifestyle. To be an effective advocate, the principles of advocacy necessarily permeate everything one does. It is an integral part of one’s identity and the way in which one conducts one’s life.
- Advocacy is the catalyst for change – not the change agent. An advocacy initiative targets, provokes, and influences change. An advocate may create a climate for change or bring decision makers to a position of having to act. But it is conflictual for that advocate to then participate in or direct the change process. Change in policy or practice must be developed by those responsible for its implementation.
- The process of advocacy is incremental. Each advocacy initiative builds on the one before. Small successes are cumulative. There is a need for continual assessment and re-organization to sustain momentum. Major initiatives undertaken by the Advocacy Office have often spanned more than five years. For example, unsafe practices in the use of intrusive measures or the management of young offenders, separate and apart from adults, are both advocacy initiatives that have required ongoing vigilance and sustained pressure. It is important to keep advocacy goals focused and in sight.
- Equalizing the power base is a primary function of advocacy. Advocates help young people to access legitimate authority and to learn skillful ways of disagreeing with people. This is more easily achieved when children and youth feel safe and heard.
- In preparing for any advocacy initiative, it is important to estimate the costs involved – both

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economic and personal costs. When “picking your battles,” these costs need to be weighed thoughtfully. Advocacy is about shifting the status quo or unblocking the inertia, whatever the endeavour, whether it be institutional culture, jurisdictional barriers, policy limitations, gaps in service, or protocols for practice. Advocates face tremendous resistance to proposed change even if that change is necessary or in the best interest of the child or the system. Advocates need to be fully prepared to confront that resistance.

- Champions need to be identified to move an initiative forward. Each community has a wealth of natural advocates for children. Mobilizing these advocates and nurturing those relationships is a critical component of successful advocacy.
- As a Child Advocate, I’ve learned to bring courage and dignity to every advocacy initiative. Advocates must anticipate retribution and reprisals for case and systemic advocacy. If the case intervention is not managed, the client (child) will experience retribution for having voiced his or her concerns. Retribution can be direct (such as loss of privileges for the child or loss of access to that child by a parent) or indirect (such as staff collusion with peer-on-peer violence). Retribution against the “whistleblowers,” who may be staff or caregivers, must also be predicted and prevented. Reprisals are frequently directed at the advocate as the “messenger” or “catalyst.” As the Child Advocate, I had never considered that there would be dangers or risks involved in the position. The threat of physical harm, personal property damage, intimidation tactics and bullying, has been common over the past ten years and is now anticipated. Advocacy requires courage of conviction, the determination to stand your ground, and the ability to put personal fears and interests aside.
- Of paramount importance is to celebrate successes; to be your own historian and consistently tally and record those successes. Retrospective reflection instills hope and strengthens resolution. For example, a recent settlement in favour of young people who reported harsh treatment in a correctional facility is an important milestone. Fear of retribution, fear of denial, the placing of blame, shame and trauma historically inhibited victims of institutional abuse such that their stories were only told as they approached adulthood and gained the courage to report. Children and youth now know that they can speak about their care and be heard. The Child Advocate will be a vehicle for that voice. This reinforces the Child Advocate as a fundamental safeguard for children in care or custody.

**Positioning Child Advocacy as a Government Agency: The Dilemma**

There are four necessary components of child advocacy: independence, statutory power, accessibility, and exclusivity to children. In Ontario, the Advocacy Office is mandated under Sections 102, 103 and 108 of the *Child and Family Service Act*. It is legislated that children in care or in custody are informed about the Advocacy Office in a language suitable to their development. It is regulated that children are informed at admission and during plans of care about their right to contact the Advocacy Office. Information about the Office and how to access an advocate is to be posted in all residential settings. In 1998, the Advocacy Office shifted from its responsibility to provide advocacy for developmentally disabled adults to the provision of advocacy exclusively for children and youth.

In Ontario, the Child Advocate reports to senior levels of government in the Ministry primarily responsible for services to children and families. The Child Advocate negotiates with that same Ministry to ensure children receive the care they deserve. This creates a dynamic tension between Ministry officials and the Office. Advocates are constantly balancing their relationship with decision makers against their responsibility to their client. On occasion this involves conflicts of interest. Advocates and bureaucrats have learned a healthy respect for each other while maintaining a social service system that is open and accountable. This emphasizes how important it is for advocates to create and nurture alliances inside and outside the government. It also offers a multi-layered approach to advocacy strategies. Most successful initiatives have simultaneously created pressure from within and outside the constellation of decision makers. The internal positioning of the Advocacy Office facilitates accessibility to both sources.

**Advocacy for Children at Risk**

Over the past decade the Advocacy Office has witnessed dramatic changes in the population of children served. Children present with a greater complexity of needs. They often have neuro-developmental disorders, medical complexity, or cognitive impairments. It has been recently acknowledged that deprivation and chaotic family lifestyles contribute to a host of neuro-psychiatric problems. These children exhibit more extreme behaviours.

The clinical capacity in Ontario to assess these children is excellent. However, treatment strategies appear not to have kept pace. Children’s Mental Health Centres, which are clinically most able to deal with children with complex needs, function at capacity and maintain long waiting lists for service. These resource intensive children with special needs are therefore managed in group homes which may not be fully equipped in terms of clinical and staffing resources to manage the complexity of needs presented.
These agencies, which are dependent upon per diem funding to function at capacity, may not always be able to match the needs of children with the resources required to adequately care for them. Sometimes staff have managed the behaviour of children by employing techniques that worked historically, but are ineffective with the constellation of symptoms children present with today.

The recent amendments to the CFSA commendable and broaden the safety net for children living in neglectful, chaotic, or abusive family environments. Children are coming into care in dramatically increasing numbers. For the most part, these children present with a range of mental health needs. Presently, there is a lack of adequate resources to manage increased referrals both in terms of numbers of referrals and the clinical capacity. Furthermore, staff in the group homes that care for this province’s most vulnerable and difficult-to-serve children are among the lowest paid human service professionals. Society presently appears to devalue the work of child and youth workers and consequently there is diminishing interest in pursuing this profession. Staff turnover contributes to a lack of continuity and further attachment disruption for these children. Staff are young with minimal experience and often aren’t offered the necessary training and supervision. There appears to have been a lowering of the bar in terms of standards and expectations of group home providers. In some circumstances, the living conditions of children in care are deplorable.

Since 1996, six children have died in group homes or institutions in Ontario. Two children died during the use of physical restraints, two children died from successful suicide attempts, one died from assault by a peer, and one youth died of neuroleptic malignant syndrome. The rate of one death per year of children in care is unprecedented in the province of Ontario. All of these deaths were avoidable and unnecessary. There are lessons to be learned from these deaths. Society collectively needs to draw the line in the sand.

SO MUCH / IS THE JOURNEY!
THE ROLE OF SPIRITUALITY IN MENTAL HEALTH AND ADVOCACY

Randy Goossen* 

“Hope deferred makes the heart sick, but a longing fulfilled is like a tree of life.” Proverbs 13:12

The other day, one of my patients, Kevin, spoke of his depressive feelings in terms of “hopelessness”. Having the challenge of a serious mental illness and substance abuse, he finds his personal losses, separation from family, and the day to day challenge of coping with friends who encourage his drug habit, a struggle. When our conversation turned toward his spirituality, he expressed his experience of God as someone who used ‘nudging’ instead of “a baseball bat in the sky” to direct him. As we spoke about this meaningful topic, he became more animated and was able to view other contributing factors that made him ‘blue’. His response is not surprising, as I have other clients who have expressed the value of their faith in their recovery process. Mike spoke to me about how “God is a comfort.” Toni explained that “every day is a good day” and went on to say that his faith “can combat such things as onslaughts of emotional distress, worry, depression.” From his perspective, “even though [he has] a mental disease… life is nothing but anybody else’s 9 to 5 occupation.”

Much of our emphasis in psychiatry has been to foster an environment of recovery. Most programs have approached this challenge by reflecting on what is ‘client centred’ or by being ‘client focused’. This approach has often been couched in the bio-psycho-social model which Anthony1 and others have written about. The model upholds the recovery ideal as it pursues a rehabilitative path to wellness. Anthony stated that recovery “is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness.” The factors that influence an individual’s health include their heredity, psychological makeup/temperament and social connections. What has often not been addressed is the role that a client’s belief system plays in the process of their recovery.

For decades, the medical profession has seen the power of the placebo effect. What is it about human nature that allows one’s belief, in the therapy and the therapist, to influence the outcome? The fact that placebo or ‘as if’ treatment can be up to 30 to 50% as effective as the actual treatment itself, should lead us to marvel how our brain works. The literature points out overwhelmingly the benefits of religion/spirituality in the health of individuals. Gone are the days of skepticism about the positive effects of religion on health. Although we live in times of remarkable biological advancements which point out the intricacies of the brain, over the past two decades more is being done to explore the realm of faith in the context of its effects on chemistry and emotional outcomes.

* Judy Finlay, Chief Advocate, MSW, Office of the Child and Family Service Advocacy

A recent Canadian study of 88 consecutive inpatients by Dr. Marilyn Baetz in Saskatchewan discovered that those that attended worship services regularly had lower Beck Depression Inventory (BDI) scores, shorter current lengths of stay, lower rates of alcohol use (current and lifetime), and reported significantly greater satisfaction with life. A recent evaluation of my Program of Assertive Community Treatment (PACT) clients demonstrated that up to 75% of clients interviewed reported that they had a religious faith and 85% agreed that ‘faith is important in every day life.’ In contrast, a study of 231 psychiatrists in Britain found that only 27% of psychiatrists reported a religious affiliation and only 23% had a belief in God. Ninety-two percent however, “felt that psychiatrists should concern themselves with the religious concerns of their patients.” Interestingly, when it comes to spirituality and religion, many physicians treat these more of a ‘taboo’ than sexual and financial concerns. Although the ‘psychosocial rehabilitative’ (PSR) approach is vital for most professionals to meet the needs of clients who require the education and resources to build their skill set post-illness, the spiritual dimension of our clients is often left untouched.

There has been a reluctance at times to view clients’ spirituality as an important resource. Professionals have avoided questions about spirituality out of fear of ‘awakening’ delusional or hallucinatory symptoms or out of the belief that abstract thought is not attainable in their seriously ill clients. Simple questions such as “What brings you joy in your life?” or “What brings meaning to your life on a day to day basis?” can go along way to exploring the depth and width of our clients’ hopes and joys that bring purpose to their lives. Frankl spoke of the existence of an ‘existential vacuum’ that people seek to satisfy. That which brings meaning to life may stir change within, ‘outside’ the realm of a bio-psycho-social mindset. Of late, there has been less hesitancy to include the ‘spiritual’ within the PSR bio-psycho-social model. The author and other academics have begun incorporating the concept of the ‘spiritual’ when teaching medical students. Cooper argues: “The biomedical model of mental illness has contributed significantly to our understanding of major mental illness, but little to true recovery. While medications may help one’s behaviours become more acceptable to society, they do nothing to put one’s shattered soul back together.” This ‘hole in the donut’ (Figure 1) concept demonstrates that, that which is ‘spiritual’ – hope, faith, beliefs, and purpose brings about change and healing. Whatever fills the ‘vacuum’, may determine various aspects of one’s life including their personality, their sense of wellbeing, and even from a religious perspective their ‘salvation’. The ‘core’ of the individual holds on to what is interpreted as meaningful, that which holds value. It is not surprising then, that the scriptures say: “For where your treasure is, there your heart will be also.” Matthew 6:21 (New International Version.)

What role can spirituality play in mental health? W. Patrick Sullivan writes that

“Spirituality
• can serve as a primary coping and problem-solving device...
• can be an important aspect of a personal social support network...and
• can help sustain a sense of coherence and meaning in life....”

Many clients today have little family to create a holding place for their recovery. A ‘fellowship’ of believers may create a sense of cohesiveness and belonging which allows for self reflection and the development of identity. The structure of that setting may influence the individual to avoid self destructive habits such as drug use and thus pursue other altruist goals of living a life free of entanglements. The social value of such relationships promotes behaviours which enhance the individuals support network and provides purpose for change. It is important to note that anytime a ‘hierarchy’ of power exists however, there is the potential for harm.

‘Relationship’, whether in the therapeutic alliance with one’s therapist or with loved ones in any case, seems be one of the keys in the road towards wellness. The evidence of the negative impact of relationships on the serious ill cannot be ignored and has been well researched previously (Leff ) There is a tendency towards negative outcomes for clients suffering from a serious mental illness who live in high ‘expressed emotion’ (EE) environments. Similarly, clients may be harassed or exploited in certain religious groups or cults. Much can be said however, about the value of support and friendship for clients suffering in their loneliness.

Because one’s psychosis or beliefs are played out in the ‘perceptual zone’, what is ‘spiritual’ or what is ‘illness’ may require some expertise. In appropriate circumstances, the prudent and cautious exploration of our client’s relationship with the Divine may be helpful to clarify oppressive or destructive thought patterns. Where concerns are raised outside the professional’s comfort/expertise in practice, a referral to a chaplain, clergy or spiritual advisor may guide the process to find the ‘open space’ to allow grace and growth. This role of spiritual exploration in effect is a form of advocacy which may have profound ramifications for the client who is without hope.

Ironically, professionals are in a precarious position of power which can either ‘close space’ or ‘open space’ towards clients becoming well. An attitude of humility and grace, when dealing with clients’ perceptual difficulties, is clinically essential for every professional.

What then is the definition of spiritual? Harold Koenig (et al) states that it is the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship to the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community.” In contrast he goes on to define...
As resources for mental health care are increasingly fragmented by illness. The professional's own spirituality is rising as a significant factor when it comes to well-being. The challenge to professionals is how to 'open space' for their clients to discuss that relationship and responsibility to others in living together in a community.”

Lawrence Seidl suggests that “Spiritual health is that aspect of our well-being which organizes the values, the relationships, and the meaning and purpose of our lives.” Patients who have recovered their lives from the ravages of their illness may find themselves coping with significant loss. Duckworth et al note “that patients often search for a sense of purpose and spirituality as their symptoms remit to a substantial degree…. A large number of them understandably yearn to return to there former hopes of what they had wanted to become but instead must grieve this loss and attempt to find meaning and purpose in their reconfigured lives.” Having a spiritual or religious framework to understand one's life, gives people the “cosmic orientation” to regain a new direction in life.

As resources for mental health care are increasingly measured in 'best practice' terms, the value of spirituality is rising as a significant factor when it comes to well-being. The challenge to professionals is how to 'open space' for their clients to discuss that which brings hope to their lives. Simple questions about purpose and meaning may reach deeper and may assist the client to establish the 'self' that has been fragmented by illness. The professional's own faith may provide the challenge to view patients as Martin Buber did i.e. 'I – Thou' context which may foster an environment of hope and healing. It is in this relationship that the professional and patient often attempt to mirror the respect found within many religions. Within the context of relationship, healing begins. If there is anything that marks the importance of advocacy, it is in the arena of relationship; one that encourages respect and promotes understanding.

In conclusion, the role of spirituality in mental health and advocacy needs to be seen in the context of relationship. Hope, purpose, and meaning generated through one's faith places individuals on the road to healing. Professional's willingness to explore their clients' belief system may go along way in finding 'the person' behind the mask of mental illness.

I leave you with words from a song I wrote during a time of personal searching. I hope it encourages the reader to look beyond the finite and find hope, hope in relationship:

“How did You find me, lost in my mind? Yes this usually happens just about this time I need a pilot, one so I can race the seas And I need an answer, one … that's just for me.

Who could have told You, just where I was? Yet You came to find me, showed me all Your Love I need a rudder, one to set these sails a course And I need a quiet place, And I … I think I've … found the Source.”

RBG


Introduction

This paper reviews the historical development and current state of advocacy of religious rights in Ontario. It traces the evolution of religious rights from their being an established mode of cultural community control through the current individual, minority-based advocacy. Based on its perception of the trends, it sees religious rights advocacy as a major factor, not only for the individual identity, but also as a primary agent for defining Canadian cultural identity as a mosaic of interdependent faiths and cultures.

Historical Context

The advocacy of any human right is culturally driven. Even the United Nations’ “Universal Declaration of Human Rights” (1948) reflected the aspirations of Western European and North American democratic ideals, while being in sharp contrast to the political logic of most nations. Particular human rights have had precedence based on both the social acceptance of the particular human right itself and the social acceptability of the individuals seeking to have their rights acknowledged. Historical perspective abounds with examples of both principles affecting the rights of individuals based upon the cultural perception of race, gender, or sexual orientation. Individual rights also continue to be mitigated by governmental fears and desires.

Historically, the rights of religious practice affecting spiritual identity and care in Ontario were structured through an Anglican Christian lens, as the official church of Upper Canada, with legislated exception given to the large, similarly minded, Roman Catholic minority. With these perspectives imbedded in both the Province’s school system and hospitals, it affected the day-by-day cultural perceptions of human identity and community. This vestige of British colonial power is one of those perspectives we actively chose to keep as part of our national, and particularly our provincial identity. Here there was not to be a “separation of Church and State” as in the United States, but a state informed by the community ethics of religion. This was recently evidenced in the suit brought against the Roman Catholic, Presbyterian, and Anglican churches for their involvement in native residential schools. The concept of the original design was to create a place of refuge, where “like individuals” (physically, mentally, socially, or culturally deprived) could be with their “own kind” in a protected community. It does not mean these particular Christian ethics were in any way responsible for the philosophy of the “white man’s burden” and its uniquely cruel nineteenth century ideal of the “concentration camp,” which, most twentieth century, Western governments applied to various identifiable “socially undesirable” minorities. It is centered more directly on the concept of the socially redemptive value of faith and those members of the community who deserved the rights of the faithful (and productive), including full access to worship and the
sacraments (including marriage). In other words, most identifiable social subgroups were allowed only those human rights the government felt they were capable of “handling,” based on the social understanding of their generalized abilities. No allowance was made for individual capacity, family support, cultural identity, or other affecting factors; these individuals were considered “Citizens of the World.”

World War II brought major disruption to this aspect of social order and these community ideals. Post-war institutional administrators and clinicians were hired from the ranks of returning veterans. Their army careers had taught them the values of uniform services, institutional order, and behavior modification.

Religious rights were served by worship services given by either the Protestant, Roman Catholic or Jewish institutional chaplain, as an institutional program, intended to reinforce the institutional mission with residents. The faith and family perspective of European and Asian immigrants beginning in the 1950s challenged this ethic of an imposed, separate, institutional order of religious purpose and community life.

By the 1970s, the concept of a community accepting and possibly benefiting from the “differences” of its people began to be seen as a social norm. The institutions that had separated individuals from the community, based upon their disability, began to focus on the reintegration of residents to the community. Illustrations of this include the 1976 removal of section 14 of the Juvenile Delinquents’ Act that had allowed the indeterminate imprisonment of teenage girls for being “unmanageable.”

Canadian society began to disassemble its segregation of individuals with undesirable social habits, deformities, and handicaps. In order to accomplish their “social repatriation,” it was deemed in residents’ best interest to allow them the practice of limited human rights within their respective institutions. Allowing Natives in some provincial corrections facilities the previously illegal cultural practice of an occasional sweat lodge first evidenced this.

Provincially hired, clinically trained, professional chaplains, now present in most provincial facilities, took advantage of this cultural shift to begin introducing other religious services, celebrations, and personal practices that were unique to the resident’s identified faith group. Institutionalized people began to claim individual and group identity based on their religious practice. Patients began “changing religions” while still residing in the institution and they wanted their records to show it. Long-time residents began asking to have their “church membership” transferred when leaving the institution.

By 1985, efforts were beginning to change the provincial government, Ministry, and institutional perspective through religious rights education. The “Multifaith Calendar” and “Multifaith Information Manual” were produced and given to every institution administrator, chaplain, Ministry program manager, and provincial politician. The Ontario Provincial Interfaith Committee on Chaplaincy became the Ontario Multifaith Council on Spiritual and Religious Care.

A formal “Memorandum of Agreement” (December 3, 1992) was signed by the provincial government Ministries of Health, Community and Social Services and Correctional Services and 22 faith groups, indicating the nature of their respective responsibilities in providing for the religious rights and spiritual care of those in government institutions and programs. The Memorandum was reaffirmed by the current government in 1999. During this same time period, the courts have continued to put a finer definition of what constitutes a “religious right.” Recent court cases have dealt with such items as appropriate head wear or what defines a religious custom. The Province has increasingly devolved its responsibility in the provision of human rights by giving the control of many of its facilities and programs to community boards, without clear contracts of responsibility in this area (group homes, community support programs etc.). Faith groups (e.g., Sikhs, Muslims, Buddhists, Seventh Day Adventists, Jehovah Witnesses) whose worship practices, personal disciplines, and celebrations have not fit comfortably within Ontario institutional culture are more frequently receiving institutional services unprepared for their unique needs.

The Current Situation

The acknowledgement of individual human rights of those served by the government, particularly in residential facilities, has moved forward by direct advocacy. The Ombudsman, Psychiatric Patient Advocate Office, and the Office of Child and Family Service Advocacy have, one case at a time, raised the level of social awareness and the breadth of understanding of human rights to the institutional culture of the Province. Most significantly, they have “individualized” the concept of human rights for those people dependent upon government services for their maintenance and support. They have been successful in changing this major social construct in less than 30 years. The individual rights of those in institutional care are still regularly violated, but in most cases, not with impunity. Most institutions maintain a respect for the advocacy of their clients’ rights.

Even for advocates and clients not all rights are equal. Social, political, and economic forces and the group consensus of the advocates all affect the orders of precedence. Currently, the individual rights that are most commonly in jeopardy are those that identify the “whole” person. These include most elements of family identity (marriage, adoption, spousal), civil redress, and religious rights. They are rights without current social prominence. This may be because these are areas of social ambiguity and change – the sort of things we don’t talk about in public. Today, rights dealing with race or gender have gained a high priority in the public mind, while those of
accessibility and informed consent have diminished and the rights of association and speech are being actively challenged.

Institutional and public perception of the value of a particular right also affects the ongoing acceptance of that right for a particular group. This is exemplified by a psychiatric patient’s “right to refuse treatment,” currently in public debate through Brian’s Law, the amendments to the Mental Health Act in December, 2000. Thus, while support of the right of personal religious practice of an inmate may be perceived as beneficial and necessary and therefore vigorously supported and understood by the institution, the same support may not be forwarded for a psychiatric patient where religious practice could be construed as part of the ideation of the illness and therefore not as beneficial or necessary. Or, while the right of an individual to the personal disciplines of their faith can be well advocated based on their clear complaint and established precedent (i.e., Kosher or Halal diets), the systemic denial of corporate religious rights for reasons such as lack of staff, health and safety regulations, or lack of local volunteers cannot find an advocate. Conversely, advocates dealing with questions of religious rights have yet to discover resources for information and consultation outside the institution and Ministry. The Ontario Multifaith Council and others provide the breadth of information necessary for informed advocacy.

An indicator of which rights are least addressed by the respective advocacy offices can be seen in their public literature (pamphlets, etc.). Is the particular right mentioned? Is the right clearly identified? Are the expectations and process clearly stated? A review of the material available through the advocacy offices and the government unions (OPSEU, AMAPCEO), as well as media reports of systemic rights violation, would indicate that the rights of individuals to their ‘faith practices’ are not actively supported. Are we approaching the point where the rights of personal and corporate faith practice may soon be invited to receive advocacy? Who will invite those receiving institutional and community program care to seek advocacy? As government institutions begin to serve more individuals with “public faith disciplines” (diet, prayer times, modesty and abstinence), advocacy will be a key part of systemic change by asking the questions that have been hidden within the culture. Christian faith groups, whose needs have been lumped together as Protestant or Catholic, will seek their accommodations. Individuals who have had their religious identity minimized by their illness or social condition will more publicly seek the “wholeness” of their formation. Institutions and government ministries will be more confident in addressing and supporting the validation of the faith community identity of the individuals they serve. This will necessitate the further involvement and support of faith communities. Current research in mental health and restorative justice indicates this is a significant factor in a client’s successful reintegration back into the broader community.2

Most importantly, we as a province and a country will be able to clarify and strengthen the unique multicultural/multifaith interdependence that gives us our common identity, meaning, and purpose in the greater globalized world.


Emancipation in Psychiatric Facilities

Jennifer Chambers

Empowerment is the redistribution of power. In psychiatric facilities this means that power must move from those who manage or provide services to the people at the receiving end of them – “clients” or “survivors.” Because empowerment is about means as well as end, this requires the existence of a strong, independent client/survivor voice at the facility and a commitment by the organization to value it. It begins with individuals’ rights of ownership over their own persons, and extends to c/s decision-making power over policy and practice at the facility. To grow this essential paradigm shift in mental health service, various methods can be used to “fertilize” it (without using the more common fertilizer, which tends to have the opposite effect).

The word “empowerment” can mean many things. It can obscure the real stakes – POWER – and thus be either a Trojan horse for genuine change, or a small gift bestowed by the mighty upon the powerless. The French term is clearer, “d’appropriation du pouvoir,” which can translate as “the appropriation of power.” In this phrase it is obvious what needs to happen. For some people to have more power, others need to have less. The goal is to change power relations between people. This will be the model of empowerment sought.
in this article. Ultimately empowerment must occur on two levels: individual and organizational.

The most fundamental of human rights is the power to decide what happens to your self. The most (legally) disempowered people in this country are those who are both in custody and required to submit to body and mind altering treatments. “A particular treatment decision may be contrary to deeply held social, medical, political or religious values held by a person with a mental disability. Coerced treatment may violate an individual’s sense of control over his or her life, health and body. While it may be difficult to quantify the subjective feelings of humiliation and degradation caused by coercive treatment, there is no doubt that these feelings may be very intense.” The law allows this to happen in various circumstances, but in recognition of the seriousness of this situation has put in place legal safeguards. To what degree do they alleviate the powerlessness of the individual in a psychiatric facility?

Legal rights in psychiatric facilities are the primary means of redressing the imbalance of power between the professional and the individual client or survivor. For this to work, rights must be adequate, and both accessible and meaningful in practice. Many people in psychiatric facilities never know of important rights that they possess. An example is the right to informed consent. Clients or survivors seldom know that their doctors are legally required to inform them of possible risks of treatment as well as possible benefits, and of alternatives to this treatment. This right is rarely properly upheld, so it is purely a paper right for most people. Being voluntary is a relatively powerful position if you know it is, yet when nurses tell a voluntary patient that he is not permitted to leave the ward, he unhappily complies, not knowing his rights. So knowledge of rights is one criteria for individual empowerment.

Some suspension of liberties triggers rights advice, and an opportunity to appeal to the Consent and Capacity Board (CCB). To do so, the person must brave the displeasure of those in control of her or him on a daily basis. According to the statistics from 2001, one will lose the appeal about 94% of the time on treatment capacity, 89% on involuntary status. In this case the c/s has knowledge of his or her rights, and is able to access the rights protection process, but the arbitrariness of the process means the person has limited meaningful power in the situation.

Much powerlessness in the institution falls into a grey area of coercion that may not violate a right but does remove real choice. For example, while someone has a legal right to consent to treatment and be informed of alternatives, a person who wants assistance may be told that if she or he will not comply with one treatment (medication), they will get no other help. For people with the theoretical power to choose, reducing it to yes or no makes that power as small as possible. When a voluntary patient is told she will be made involuntary if she tries to leave, has she more or less power than an involuntary patient? Remember that an actual involuntary patient is told of her right to appeal.

And lest it seem that all mistreatment of psychiatric clients/survivors is subtle, according to some of the rare publications in journals on this topic “physical or sexual abuse by professionals of clients occur frequently.”

There are so many ways of disempowering a psychiatric client or survivor. What can help clear the way for a person in a psychiatric facility to have full possession of their human rights?

Preferable to battling right by right would be a shift in attitude so that people in the psychiatric system are recognized as experts on their own lives, with their own lives to live. The predominance of the medical model explanation and treatment for all mental disturbance and emotional distress is maintained because the power structure exists to support it, not because it has been proven to be the best approach for most people. Determinants of well-being and self-identified needs long advanced by c and s’s have a great deal of evidence to support them. But there is little effort on either an individual or systemic level to put the resources into nonmedical supports to the degree warranted - which is indicative of the power based nature of much decision making.

A Bill of Rights that both emphasizes and extends existing rights can be a helpful instrument of empowerment. The emphasis on existing rights can be an opportunity to inform c/s’s of those rights and to remind professionals to abide by them. An extension beyond mere legal rights is required to address the other losses of power that come from interacting with an institution. An organization that chooses to adopt a meaningful Bill of Rights is taking a position that it recognizes the c/s as a full human being, complete with human rights and dignity. For this Bill to improve the balance of power it must be based on real experiences of power deprivation, such as those already described. If some rights are excluded because mentioning them acknowledges facts that the institution would prefer to deny, this is a misplacement of priorities. When a truly meaningful Bill of Rights is created, implementation is the next challenge. What is needed is access to a full range of information, meaningful choices, a means of addressing wrongdoing, and decision-making power that has an effect. For this, education and independent advocacy is required.

Education about rights, by and for clients/survivors is ideal. Knowledge is power. And empowerment is about how things are done as well as what gets done. When c/s’s educate each other the medium is also the message. And “through understanding our rights we increase our sense of strength and self confidence.”

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Once aware of their rights, people in facilities can still need someone to assist in accessing them (someone with more freedom then they currently possess). To their credit, most psychiatric institutions in Ontario have advocates who are not employed by the facility itself. Advocacy is from ad voce, to give voice to. It must be a clear voice, so it needs to be independent of any concerns other than the c/s’s. Individually and organizationally, to be fully empowering advocates should be accountable to the people for whom they speak. And for advocacy to restore any actual power a mechanism of enforcement as well as monitoring rights in the facility is required. Right now there is no clear method of rights enforcement in use in any facility in Ontario. Enforcement may require going outside the facility, e.g., to professional Colleges or the legal system. Unfortunately, protecting people who exercise their rights from retribution is necessary but almost impossible.

Fundamental to the liberation of all oppressed people is for members of the group to come together and find their own voice. “Empowerment work involves ... the process whereby the group as a whole finds and find their own voice. “Empowerment work involves ... the process whereby the group as a whole finds and find their own voice. Empowerment work involves ... the process whereby the group as a whole finds and find their own voice.

Clients and survivors of a psychiatric facility need to be able to talk about shared experiences and what they mean without the presence of anyone outside the group. Consciousness raising, the tool of many people’s liberation, is how we move from individual oppression to collective action. If the administrators of the psychiatric facility have a genuine desire to respond to the real needs of the population they serve, they will support clients and survivors having their own voice, chosen by their own people to represent them (such as Councils).

For this collective voice to have an effect the c/s group requires a fair share of resources, “the right to access and participate in the allocation of resources.” The voice of this group could reasonably be turned to systemic advocacy, representing c/s interests. The independence of the group needs to be maximized by all of its policy and issue direction coming from its members, and by its staff being accountable only to it.

Finally, the psychiatric facility has to agree to share power. “Services are often paternalistic and a medical model of care puts great weight on the view of the doctor. Empowerment requires control over service delivery and the planning, development and management of care.” Agreements will need to be negotiated and attitudes will have to change. One model for change is outlined in the Legislative Sub-Committee Report of 1991 that followed from the Ontario-wide consultations on the Graham Report. There it is recommended that one-third of boards and committees should be c/s’s, chosen by c/s’s.

Ultimately, a fundamental change in attitude by service providers is required to move beyond adversarial battles for rights and negotiations for decision-making power. “Professionals have to recognize and accept that they are “outsiders” and that they don’t know best.” In the meantime a daunting degree of patience is required during small shifts of power. Yet the thousands of people in psychiatric facilities in Ontario right now are worth the effort. Ultimately, c/s’s coming to power could mean that dehumanizing roles assigned in the current system will be no more, to the benefit of all.

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2 The marked convergence of CUB decisions with medical opinion is surprising when reviewing research on the inability of psychiatrists to predict dangerousness (not higher than 20% accuracy on an individual level when extensive testing is used) and the tendency of psychiatrists to predict that people are dangerous when they are not, e.g., Webster C, et al. The Violence Prediction Scheme. Toronto: University of Toronto, 1994.
4 Formerly, “c/s’s”.
5 In the Bills of Rights of some hospitals a section is added telling patients what they must do. When considering the Bill as an attempt to redress the terrible imbalance of power between c/s and hospital staff this may seem like an odd non sequitur. It is actually a barometer of how intransigent this power distribution can be.
8 Ibid, p.27.
9 The Centre for Addiction and Mental Health has signed onto such an agreement with the Empowerment Council.
11 Breton, supra, note 7 at 28.
CONSUMER EMPOWERMENT: TOWARD A PARADIGM SHIFT

Stanley Stylianos

Over the past decade mental health service providers have slowly been embracing the belief that individuals with serious mental illness can recover from the debilitating consequences of their disorders. Service delivery planners are now beginning to design and implement “recovery-oriented” systems. Such systems are purported to be client-centred, empowering consumers to assume increased responsibility and decision-making authority with respect to their own care, treatment and rehabilitation. However, these developments fall short of a paradigm shift in the provision of mental health services since strategies for consumer empowerment have yet to be adequately defined and implemented. Moreover, elements of paternalism embedded within hospital and community-based programs undermine consumer self-determination and choice. While there is no universally agreed upon definition, strengthening consumer voice and providing opportunities for genuine partnership with service providers are fundamental components of empowerment; thus, “giving power” demands a shift in policy and practice, a movement away from best interest and toward consumer-identified goals and needs.

Barriers to Client-Centred Treatment and Rehabilitation

Well-entrenched institutional values and practices often impede fostering a client-centred approach. Opportunities for consumers to share their personal narratives, to become known as people and to make meaningful choices in their own treatment and rehabilitation may be limited by the treatment team’s expectations of compliance with a unilaterally developed care plan. As poignantly captured by consumer-activist Judi Chamberlin:

Being a patient was the most devastating experience of my life. At a time when I was already fragile and vulnerable, being labeled and treated only confirmed to me I was worthless. It was clear my thoughts, feelings, and opinions counted for little. I was presumed to not be able to take care of myself or to make decisions in my own best interest, and to need mental health professionals to run my life for me.1

This may represent an experience shared by many hospitalized clients who find themselves disempowered by virtue of their status as patients. Clinical decision-making may take place with minimal or no consultation with clients. While client-centred care is a stated objective for many programs, it may be in conflict with other competing philosophies of intervention. For example, shifts in the conceptual framework of mental illness and its treatment could potentially narrow the focus of client consultation and engagement. This is the case where mental illnesses are viewed as “brain disorders” and treatment is limited to pharmacological therapy; in addition, practitioners specialized in biological psychiatry may not have the requisite skills to successfully build therapeutic relationships and actively involve clients in their own rehabilitation and recovery. As psychiatric rehabilitation proponent William Anthony has noted, “…the mental health field seemed to be treating people with severe mental illnesses as if they were impaired body parts – in this case dysfunctional brains…this partitioning of the person into body parts was part of a legacy of putting up walls that divide us from one another, and from our whole person.”2 Consumers may have few opportunities to voice their concerns and be heard where clinicians are insufficiently sensitized to the need for individualized and holistic intervention. In addition, clients may be deprived of a comprehensive and integrated plan of care in the absence of a true interdisciplinary approach.

Failing to provide clients with a range of treatment options and the power to make personally meaningful choices is a significant and widely observed barrier to client-centred practice. In many institutions, consumers are limited in the extent to which they can influence both their individual care and the policies and practices that shape the treatment environment. This is particularly apparent in forensic mental health settings, where risk management appears to take precedence over rehabilitation and recovery; in these environments, clients are often restricted to a narrow band of choices. Broadly stated, clients are not encouraged and supported in articulating their own needs and preferences, but are compelled to make forced choices, edging treatment in the direction of coercion. Similarly, where treatment environments are insensitive to cultural diversity, consumers from different cultural backgrounds may be forced to make choices that are unresponsive to their expressed needs and values.

Approaches to Client Empowerment

A broad strategy is needed to reduce barriers to client-centred care and to facilitate client involvement as full partners in their own treatment and recovery. Empowerment approaches should include a range of individual and systems level options. Organizations need to strengthen and support the role of consumers in leading the treatment and rehabilitative process. In part, this can be accomplished by assisting them in articulating and achieving personally meaningful goals. Clients must be invited to participate in clinical decision-making through active collaboration with healthcare providers. Team reviews should be designed to support this end; inclusion in clinical planning should take into account
individual communication styles, preferences and skill levels. No client should be compelled to attend team reviews, but should be offered a range of opportunities for collaboration with staff. True decision-making power can only be achieved where genuine choices exist and, for this reason, clients need access to a range of individualized and culturally sensitive treatment alternatives.

Clients need to be involved in a substantive way in the life of the organization. This means being included in key organizational activities, decision-making committees and work groups. The client perspective should be reflected in policy and practice, research development, quality assurance and program evaluation, hiring practice and accreditation processes. Organizations must assume the responsibility of providing the necessary human resources, infrastructure and financial support to ensure the success of these initiatives. Supports must be made available that address client identified needs. Consumer involvement must be supported through opportunities for ongoing education to develop both the knowledge and skills required to contribute to organizational change and development. As clients assume an active role in organizational life, staff may need to redefine their own roles to accommodate the shift in client responsibility and power.

Patient councils may be unique structures to facilitate client empowerment. Ideally, developed through memoranda of understanding, councils are quasi-independent bodies representing the perspective of clients. Councils can undertake a broad range of advocacy initiatives on behalf of participating members. These include: systemic advocacy; participation in decision-making activities and committees; the provision of information and education to clients, professional staff and the community at large; canvassing of a broad base of clients through ongoing outreach and consultation; and the development of client driven research studies. Councils have the potential to unify the voice of consumers around critical areas of quality of life, care and service delivery.

Councils can also significantly reduce stigma by educating staff and the public. Such educational efforts are pivotal to sensitizing individuals to the client perspective. Education provided to clients can assist them in becoming politically aware and in developing self-advocacy skills. Councils may be effective at mobilizing peer support through diverse and well-coordinated initiatives. The success of the patient council, however, hinges on the organization’s commitment to its support; this support must include the provision of necessary material resources and the development of an effective liaison mechanism.

**Conclusion**

Client empowerment may be the linchpin in the development of a recovery-oriented framework for the delivery of mental health services. Organizations have an obligation to facilitate both the process and goal of power sharing with clients and should undertake a range of empowerment initiatives. Consumers have the potential to make an important contribution to the governance of the agencies that serve them. Strengthening client voice will lead to a genuinely client-centred perspective that can positively impact program services and organizational culture. Clients should be supported in assuming increased responsibility for their own recovery by being given the power to make meaningful decisions regarding their care, treatment and lives.

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**ACCOUNTABILITY AND ADVOCACY**

Steve Lurie*

If organizations were truly accountable, would there be a need for independent advocacy services? This paper explores the issue and suggests that the answer is yes. It is important for organizations to be accountable to their various stakeholders, but it is also necessary for independent advocacy to exist. Neither condition on its own can guarantee public good, but both conditions have a role in fostering it.

We begin by exploring what we mean by accountability and some of the challenges in being accountable, and suggest that an ethical auditing process is one strategy that an organization can use to reflect on whether it is both doing the right thing and doing things right.¹ We then turn to the role individual and systemic advocacy can play in enhancing accountability.

April 2000 was an interesting month in the accountability sweepstakes for voluntary sector organizations. The National Society For Abused Women and Children is alleged to have received donations totaling over $119,000 over the past two years by “claiming to operate a domestic violence crisis line and support groups for battered
women and to provide financial donations to shelters for abused women.\textsuperscript{12} The \textit{Toronto Star} investigation of the group showed it provided “none of the services it promised even though it was a registered charity with Canada Customs and Revenue Agency.\textsuperscript{3}"

On April 10, the Ontario Minister of Health and Long-Term Care announced that she was notifying the Hamilton Health Sciences Corporation of her intent to appoint a supervisor to take over operations and develop a recovery plan for the hospital.\textsuperscript{4} The supervisor would hold the powers of the hospital board and administrator. The notice was a result of a joint operational review of the hospital to examine recurring deficits and governance that found “invisible leadership and ineffective management at the senior level\textsuperscript{5}” (p. 36) and a Board that had difficulty focusing on its role as governor and steward\textsuperscript{5} (p. 58).

This fall and winter (2002-2003) we have seen similar examples: the \textit{Toronto Star} exposé on charitable fundraising and the report on the Sudbury Regional Hospital detailing mismanagement and recently posted on the Ministry of Health and Long-Term Care website.

These events may frame public perceptions that Walter Stewart and John Bryden are right: Canada’s charitable or non-governmental sector is “rife with improper and even illegal activities\textsuperscript{6}” (p. 8). This frame of corruption and mismanagement in non-government organizations is not unique to Canada. Herzlinger asserts that US health and social service organizations “cannot afford the erosion of public confidence that has followed recent scandals at some of our best known nonprofits”\textsuperscript{7} (p. 2). She laments that “there is still no way to systematically gather and disclose” information about voluntary organization performance\textsuperscript{7} (p. 2).

Moss Kanter and Summers note that while performance measurement in any organization is complex, not-for-profit organizations face particular challenges. Financial measures, such as return on assets or profit, which allow for measurement of market satisfaction and efficiency, are reasonable measures when applied to for-profit organizations. Non-profit organizations tend to be assessed in relation to their mission or services, which are “notoriously intangible and difficult to measure”\textsuperscript{8} (p. 154). Donors, clients, funders, program staff, and board members may all have different perspectives about how well the organization is doing due to “the difficulty of effectiveness measurement and the varying standards of donors and others”\textsuperscript{8} (p. 155).

Multiple and sometimes conflicting goals among programs or subunits makes the development of organizational performance measures difficult because of complexity, and quality is difficult to measure because it tends to be subjective\textsuperscript{8} (pp. 155-7). Moss Kanter and Summers argue that the limited reliance on client fees reduces focus on client feedback and the focus of measurement “is likely to shift away from output to input”\textsuperscript{9} (p. 163). Internal stakeholders often assume the worthiness of their activities and sometimes “failure to achieve goals is taken not as a sign of weakness … but as a sign that efforts should be intensified”\textsuperscript{8} (p. 164).

Like Herzlinger, Moss Kanter and Summers, Murray and Balfour’s review of health and social service evaluation practices in Canada suggests that the holy grail of organizational performance evaluation is not yet in sight. “It is still more talked about than practiced … it is often sporadic, short lived, and flawed. Evaluators draw their conclusions about performance from inadequate data, informally gleaned impression and preexisting beliefs”\textsuperscript{9} (pp. 4, 56).

Murray and Balfour identify the need for external evaluators to be used “because it is often difficult for people to be objective in assessing their own performance\textsuperscript{9}” (p. 3). This contrasts with Moss Kanter and Summers who identify the problems that multiple stakeholder perspectives create for performance measurement, but do not suggest external evaluators\textsuperscript{9} (p. 158) and Herzlinger who argues that public disclosure and government oversight would suffice\textsuperscript{8} (pp. 2-3).

Murray and Balfour distinguish between formative evaluation, which contributes to organizational learning, and summative evaluations that pass judgement and may have positive or negative consequences such as changes in program funding levels\textsuperscript{10} (p. 4). They suggest that a culture of accountability must develop between the entity being evaluated and the evaluator and that emphasis should be placed on the development of benchmarks or relative standards, rather than absolute measures\textsuperscript{9} (pp. 56-7). Herzlinger, in contrast, argues that answering four key questions which review matching of goals with financial resources, intergenerational equity, sources and uses of funds, and organizational sustainability will suffice as “useful measures of performance” that organizations can ask themselves\textsuperscript{7} (pp. 2-3).

Moss Kanter and Summers point out the “virtual absence of control systems in human service organizations and suggest developing an “explicit and complex array of tests of performance that balance clients and donors, board and professionals, groups of managers, and any of the other constituencies with a stake in the organization”\textsuperscript{8} (p. 164).

The framing assumption here is if you can measure it, you can assess and control it. Wheatley suggests that there is a risk of developing control mechanisms that “paralyze employees and leaders … leaders have consistently chosen control rather than productivity\textsuperscript{10}” (p. 2). She suggests that we think of organizations as machines and that we expect them and the people in them to “perform to specifications with machine-like obedience”\textsuperscript{10} (p. 1).

Mintzberg states that machine bureaucracies, “which fit most naturally with mass production,” are the legacy of industrialization and are the dominant organizational form in the private sector\textsuperscript{11} (pp. 7-8). Mintzberg also asserts
that the government as machine model has been the dominant model for government, "a machine dominated by rules, regulations and standards of all kinds" (p. 80). While there has been an evolution recently to a performance control model, the “motto of which could be Isolate, Assign and Measure… (it) all too often comes down to nothing more than the same old machine management” (p. 81).

While the health and social service sector has a variety of structural forms, a predominant organizational form identified by Mintzberg would likely be the professional bureaucracy, which relies on the standardization of skills of paid staff and service volunteers. This form of organization has to surrender power to the people who deliver services and tends to result in a decentralized structure (p. 8). This leads to the complexity identified by Moss Kanter and Summers and complicates the gathering of data about organizational or program performance.

Mintzberg suggests that operating procedures carried out by professionals in this model are rather standardized, using open-heart surgery carried out in a hospital setting as an example (p. 8). While the techniques of an operation might be standardized, each client is different, and Mintzberg himself acknowledges that outcomes vary depending on what variables are measured (p. 79). These problems of measurement are magnified in community mental health services where many of the variables, such as availability of housing or levels of poverty, or medication compliance, will influence the “success” of community mental health programs. Standardized measurements of performance are further complicated by the wide variety of services they provide. As Mintzberg states, “Where is the magic envelope with the one right answer? You won’t find it. The fact is that assessment of the most common activities … requires soft judgement – something that hard measurement can’t provide” (p. 80).

In Canada, 60% of the income of the voluntary (or non-government) sector comes from governments, so government at all levels has a vested and declared interest in performance management for the sector (p. 13). Given the proportion of government funding, government approaches to transfer payment agency performance management tend to focus on compliance with regulations and standards, reflecting the machine model which still remains governments’ opus operandi.

Fred Bird, who is an ethicist at Concordia University, suggests that having good moral conversations on organization performance, through a process of ethical auditing, is a way to involve internal and external stakeholders. It begins with simple framing questions to guide organizational assessments rather than a machine-like focus on inputs, outputs, and outcomes. Here are three framing questions and some suggestions about how they can be used to involve stakeholders in fostering organizational accountability.

**To what extent is our organization fostering the good of the community?** To answer this question an organization could review its vision and mission with internal and external stakeholders. This could be done through focus groups, questionnaires, and interviews, and could be supplemented by probing questions such as: Do our activities/actions really make a difference; what are we supposed to be doing and are we spending time and resources appropriately to achieve our ends? Analysis of the responses will provide guidance on whether the organization is doing the right things relative to stakeholders’ assessments of community needs.

**To what extent are we acting in keeping with fitting standards for conduct?** This question allows an organization to focus on its process issues. Is it managing its finances according to generally accepted accounting principles; how does it treat its staff; are there opportunities for consumer and family input? These issues can be explored by committees or focus groups and indicate whether the organization is doing things right. There are also opportunities here to probe whether the organization behaves in an ethical way. Can people complain; what happens when they do? Is there silence, blaming, or responsive action?

**To what extent are we able to achieve anticipated outcomes or objectives?** Answering this question leads to program evaluation, which looks at the effects of organizational effort. This can range from reviewing processes and outcomes of programs run by the organization, to carrying out longitudinal research. Twelve years ago when I completed the Community Mental Health Snapshot for the Ministry of Health and Long-Term Care, 83% of the 309 programs reported that they measured client outcomes. While this measurement is likely a formative rather than summative evaluation, the fact that over 200 programs are now using the PSR toolkit to measure client outcomes and satisfaction demonstrates a strong commitment on the part of community mental health service providers to account for the outcomes they help their clients achieve.

Having argued that an ethical auditing process can be a way for organizations to achieve accountability, the question remains, if organizations can be accountable through this or other processes, is there a role for advocacy, when organizations engage already internal and external stakeholders in reflective activities to judge organizational performance?

Ethical auditing or other forms of reviewing organization performance, such as accreditation or operational reviews, are essentially episodic events, which while time consuming are not day-to-day operational activities. Organizations want to “do good” and be seen to do good. This can have the effect of creating a culture, which Murray has termed LGAB, or “look good, avoid blame.” Notwithstanding the exhortations in the organizational...
literature that tell us innovation requires a tolerance for mistakes, most of us who inhabit organizations would prefer not to be reminded that mistakes, errors in judgement, or unanticipated negative consequences can occur. When serious problems occur, most organizations will review the situation and take corrective action. And most of our organizations are doing the best they can on a day-to-day basis. Episodic reviews of organizational performance should be transparent and should aim to identify strengths as well as weaknesses, as an asset-based focus can generate pride and enthusiasm for organizational activities.

What should be in place for service users when things go wrong? At a minimum, all organizations should have user-friendly complaint mechanisms. Some larger organizations have found that an ombudsman function can be useful, as it creates some space through meditation for complaints to be explored and resolved. The PPAO experience over the past 20 years suggests that formalized advocacy can help resolve complaints about services and ensure that people’s legal rights are protected. The recent pilot project, which provided advocacy to ACT teams in Eastern Ontario (PPAO 2003), has shown that there is a role for advocacy in the community. Considerable time was spent helping consumers access entitlements, such as OSDP. As well, the advocate was able to help clinical staff resolve ethical dilemmas.

Measuring organizational performance and ensuring accountability is a complex task, but essential to maintaining public trust in health and social service organizations. The task itself does not preclude providing independent advocacy. Both approaches can ensure that our organizations do the right thing and also do things right.

2 Donovan K. Group got charity license with just a leaflet and a list. Toronto Star, April 8, 2000.
3 Donovan K. Abuse victims lose out as “charity” raises $116,000. Toronto Star April 2, 2000.

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PATIENTS’ BILL OF RIGHTS: A MECHANISM FOR ACCOUNTABILITY

David Simpson *

A society is often said to be judged by the way that it treats its most vulnerable citizens and the protections that it affords them. In Ontario, the Psychiatric Patient Advocate Office (PPAO) has both protected and promoted the legal and civil rights and entitlements of inpatients of the current and former Provincial Psychiatric Hospitals since 1983. Although great progress has been made with respect to patients’ rights, there is still much that must be done. The introduction of a Patients’ Bill of Rights can complement and supplement existing mechanisms, including mental health legislation, and can be used as another vehicle in advancing the rights and entitlements of persons with mental illness.

The Patients’ Bill of Rights must be enshrined in provincial legislation, include penalty provisions for violations, and be enforceable by the Ministry. There would be nothing precluding individual facilities from building on the provincial Bill and having their own Bill of Rights specific to their facility.

A Patients’ Bill of Rights can serve as one of many “checks and balances” in the system and can help to equalize the power imbalance that currently exists between the client and the system by positioning the client at the center of
the service delivery spectrum. A Patients’ Bill of Rights would clearly articulate what a client could expect to receive from the provider and what his or her options would be if any of the rights in the Bill were violated. In the past, the voice of the consumer/survivor has often been lost among those who have the power and decision-making responsibilities within the system. Consumer/survivors are no longer willing to tolerate this inequity, but instead are demanding to remain in control of their own wellness and recovery and to hold service providers accountable through new and existing rights protection mechanisms.

A Patients’ Bill of Rights must address not only patients’ legislated rights, but also other types of “rights,” including quality of life, quality of care, and the right to self-determination. Rights related to quality of life could include the right: to a compassionate, individualized and respectful care; to express a full range of emotions; to have complaints responded to; to express one’s spirituality; to wear personal clothing; to talk on the telephone; to have access to the out-of-doors; to secure space for personal belongings; to privacy; to participate in meaningful activities (social, therapeutic, recreational, educational, and occupational); to be free from physical, emotional, sexual, or financial abuse; to religious expression; and to wear and own personal possessions. Quality of care rights could include the right: to receive care in a “hands-free and restraint-free environment”; to receive information about the risks and benefits of a proposed treatment so that an informed decision can be made; to give or withhold consent to treatment; to have access to a full range of medical and therapeutic services; to have qualified health practitioners; to have the health practitioner of choice; to have access to newer medications; to have a written treatment plan that articulates the responsibilities of all parties and is updated regularly; to a second medical opinion; to know the full identities and professional qualifications of all members of the treatment team; to a discharge plan that reflects one’s choices and preferences; and to continuity of care from hospital to community and back to hospital. Self-determination rights could include the right: to be involved in all decisions that affect one’s care, life, and treatment; to determine what’s best; to have choices respected; to be free of any coercion; to have beliefs respected; and to know policies and procedures so that the rules are known in advance.

The Patients’ Bill of Rights could reinforce legislated rights, including the right: to have access to records; to confidentiality; to give or refuse consent to treatment; to unobstructed written communication; to legal counsel; not to be detained unless prescribed by law; to be free from chemical and physical restraints unless the threshold in the law has been met; to vote; and to pursue charges against anyone who contravenes the *Mental Health Act*¹ and its provisions.

A Patients’ Bill of Rights must be simple to understand, clearly defined and articulated, and all parties must understand what each right means and how to apply that right in the most liberal way possible. The interpretation of rights must be broad, inclusive, flexible, and as progressive as possible. It is imperative to have a clear and transparent appeal mechanism in place to adjudicate when parties do not agree in the interpretation or application of a right. In implementing a Patients’ Bill of Rights, health practitioners and mental health facilities must “push the envelope” and incorporate additional rights-based practices into service delivery. The Bill must be viewed as a progressive way to change institutional or corporate culture, staff attitudes, heighten accountability to the client, and promote systemic change that places the client at the center of the health care system.

A progressive Bill of Rights could potentially lead to greater client satisfaction with their care and treatment and improved job satisfaction for staff who will be able to interpret and apply a Bill that protects and promotes the rights and entitlement of all stakeholders. For this to happen, staff will need to view client complaints as a positive and not a negative experience and as a way to promote lasting and systemic change while being able to critically reflect on practice issues and how they impact on patients’ rights and entitlements. All review processes would need to be conducted by parties who are independent of the treatment team to ensure confidence and integrity in the process. This would alleviate any fear of real or perceived conflict of interest or bias in the decision made by the reviewers. Ideally, the reviewers would also include consumer/survivors, so that their perspective could be reflected in the decision-making process.

For clients to exercise their rights as espoused in a Bill of Rights they would have to know what their rights are and the recourse available to them when those rights have been violated. In order to hold staff who violate rights accountable, the recourse available to clients must have a range of sanctions, from the minimal to the severe, depending on the right violated.

A Bill of Rights would not replace a client’s right to pursue civil litigation or a complaint to the various regulated colleges should they choose this option. These options must all co-exist in order to provide the maximum protection to the client who has been aggrieved. The Bill must be seen to complement and supplement other existing avenues of appeal or legal recourse.

Health care facilities must be required to post the Patients’ Bill of Rights, to make information about the Bill available to every patient on admission, and to provide education and information sessions on “knowing your rights.” Clients must know how to engage the complaints process if their rights have been violated. A complaint process must be simple, fair, impartial and hold people to account when they violate a client’s rights. Since these
processes tend to become complicated or intimidating for clients, a process must be established that will allow them to have someone of their choice to assist and support them throughout the process. Legal representation for clients must always remain an option, should they choose. This will address any real or perceived power imbalances and inequities and address fairness issues and concerns of all parties.

There are several risks involved in implementing a Bill of Rights, including a tendency for providers to find loopholes, creating “fluid definition” of rights that change without notification or ways around providing clients with the full force of the Bill and the rights protection enshrined in it. Health practitioners or those charged with the responsibility of defining specific rights may choose to be inflexible or rigid in their definition or else rights might be denied on a technicality or through “misunderstanding” the right or the definition that is affixed to it. All of these are examples of significant rights infringements and ones that a client might find difficult to make a complaint about for fear of retaliation, retribution, or withdrawal of services. Any rights definition would need to be reviewed annually to ensure that the right had not become too narrowly defined, inflexible, or rigid in its definition and application.

Another concern is that health practitioners might embrace the Bill of Rights, seeing it as a static document that provides limits on the rights of clients. If this were to become the case, staff might not seek out other rights to include in the Bill for fear that the clients would have all the rights and they would have none. In a progressive service delivery environment, it is necessary for staff to be continually encouraged to think of new rights and entitlements to enhance and strengthen the Bill so that they do not view the existing bill as all-inclusive and exhaustive. Any Bill of Rights that remains static would be an injustice to both the clients and the health practitioners providing service in accordance with it.

The government must enact a Patients’ Bill of Rights in the interest of protecting vulnerable populations, creating a client-centred mental health system, and providing a balanced system where the rights and entitlements of all parties are protected, especially the client. Mechanisms to evaluate the effectiveness of the Bill of Rights would need to be enshrined in the law, including a requirement for annual reporting and feedback on the progress of implementation, education, and the promotion of patients’ rights in Ontario.

Consumer/survivors and their families must be the catalyst for change and be involved in any effort by facilities and government to craft, implement, maintain, and evaluate a Patients’ Bill of Rights. Failure to include consumer/survivors in the design and implementation of a Bill would be an illustration of the arrogance of service providers and a manifestation of the existing paternalistic approach to mental health care delivery in the province of Ontario. A Patients’ Bill of Rights must be drafted by those who will be directly affected. This could be the first challenge of the sincerity of mental health reform and giving consumer/survivors a greater but equal voice in the mental health delivery system.

If we are to be judged as a caring society we must put in place new rights protection mechanisms and strengthen existing ones to protect and promote the rights of individuals with a mental illness. A strong, enforceable, and comprehensive Patients’ Bill of Rights must be the next step in rights protection for individuals with a mental illness.

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**BENEFITS OF HAVING A PATIENT BILL OF RIGHTS AND RESPONSIBILITIES**

Sonya VanKruistum *

In the distant past, people suffering from various illnesses were warehoused in “asylums for the insane.” With the advent of the Consumer Movement as well as advances in medical science, we have come to some new understandings about mental illnesses. The next part of this movement is going from being merely a person with mental illness to being a citizen with a mental illness. While this statement may be perceived as semantics by some, what it implies is that people are not “done to,” but rather have rights to treatment and support that are provided respectfully, professionally, and equitably, according to need.

Part of the movement towards this has been the establishment of Patients’ Bills of Rights and Responsibilities. This then provides the balance to citizenship, which includes rights but as well corresponding responsibilities according to the person’s ability.

There are three primary benefits to the establishment of a Bill of Rights and Responsibilities. The first is that it would clearly lay out some of what patients and families should be able to expect from those who deliver service. As well, it would identify for patients what is expected of them as they actively participate in their own care to the

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level that they are able. The second is that it would inform care providers what is expected of them in terms of services to be delivered, as well as the spirit in which these services are to occur. The third is that it is hoped that a Patient Bill of Rights would expand the mindset from within the service delivery system to the broader society. This would work towards combatting the stigma and misunderstanding of mental illness that results in a lack of access to primary care, appropriate housing, employment, and education.

This effort is with the understanding that this is a small piece of much broader change that needs to happen crossing the spectrum, recognizing that given the appropriate treatment, rehabilitation, and support citizens with mental illnesses can and do live productive and meaningful lives in spite of the impact of illness.

At times when some rights are limited it becomes paramount that persons are made aware of what rights they still have full access to. In particular, with citizens with mental illnesses, while freedom of movement and decision making may be taken away this does not negate their other citizen rights. Some citizens with mental illnesses are not aware of what rights they do have and what they should be reasonably able to expect in terms of care, and until they are made aware of these rights they are not able to exercise them. A Patient Bill of Rights then becomes one of a range of means for persons to become aware of their rights. Once the citizens become aware of their rights they know what to expect of systems of care and it provides some of a number of measures of accountability for the manner in which care is provided. A Bill of Rights also becomes a tool by which the providers of care can measure their practice and care delivery. As well, the establishment of responsibilities attached to rights places the expectation that the receiver of care is an active participant in their care to the level of their ability. This then provides the mutuality of expectation.

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**LET’S GO FLY A KITE: EMERGENCE OF PEER SUPPORT**

Deborah Sherman*

Peer support, sometimes described as an alternative to medical psychiatric treatment, and sometimes as a means of enhancing it, is generally spoken of as a fairly new phenomenon, with some of its earliest examples being Recovery Inc., started in the 1930s, and GROW, from the 1950s. But surely it is much older than that; it must be as old as human interaction itself, planting its roots when our cave dwelling ancestors first learned to use speech and abstract thought, and care about one another. In our not too distant agrarian past, the “mad” were supported by family, friends and neighbours – or left to support themselves – in their own communities. It was not until we became urbanized and their behaviours consequently became intolerable to the too closely quartered general population, that “lunatics” and “idiots” were given the benefit of someone paying enough attention to form social policy to deal with them. Unfortunately, those policies consisted of chaining people up in special sections of the jail, workhouses, and eventually in asylums specifically for the insane. From that point on, living in the community was an option only for those impoverished “mad” people whose symptoms didn’t offend it, or whose family and friends were able to provide purchase supervision or treatment in it. When reform did happen it usually had to do with improving the asylums. It is only in the last few decades that the thinking has changed back to community-based “treatment” and is now slowly changing to community-based “recovery.”

To review a different sort of literature, Charles Dickens, in his 1850 novel David Copperfield, described a relationship which bears a startling similarity to the concepts of social support and peer support that consumers embrace today.

Dickens, who habitually tackled social issues in his novels and tried with some remarkable success to influence reform, populated his books with a lot of characters who were clearly “mad.” Interestingly, though, he never set them in asylums – they all functioned in the community. When he described their behaviours in sometimes comedic, sometimes tragic terms, it is clear that they were based on real people that he took the trouble to observe and interact with. It is intriguing that, for the most part, he chose to present these characters more often in the light of “living with” rather than “suffering from” their illnesses and symptoms.

Dickens visited asylums in England and on his 1842 tour of America, and wrote several journals and essays on these experiences. He was clearly appalled by the old asylum model and clearly quite favourably impressed by the private or more benevolent asylums which practised...
the “moral treatment” (relaxation, politeness in interactions, work, cultural pursuits, and religious study) endorsed by the likes of Pinel and Tuke. And yet, he still chose not to place his “mad” characters in asylums. In fact, only Mr. Dick, from David Copperfield, the most well developed of his “mad” characters, was described as having ever been inside one. And from that, Mr. Dick had been rescued by David Copperfield’s aunt, Betsey Trotwood.

Now, Aunt Betsey is an eccentric who has survived an abusive marriage and is traumatized by fear of the abuser’s return. She has some behaviours that betoken some sort of mental “difference” that could probably be identified in the DSM. This survivor has pulled her distant relation, Mr. Dick, from an insane asylum to which his family, embarrassed by his behaviour, consigned him. She firmly believes that, if provided with three simple things, he will one day prove what a great mind his really is. Those three things she gives him: a home, a friend, and a meaningful activity. For the latter, she encourages Mr. Dick to write a memoir. But his delusional obsession with the beheading of King Charles I keeps finding its way into his writings (a gorgeous metaphor for his distress over the loss of his own mind). To help him cope with these symptoms, Aunt Betsey has Mr. Dick create kites from the wasted pages of his memoir, and fly his delusions up into the sky, where he can see them as something outside of himself and under his control. A home, a friend, a meaningful activity, and shared coping techniques; in return Betsey has his companionship, his sound advice on practical matters, and a male presence to keep her past abuser wary of coming around. Is this not peer support at its best?

Whether he intended it or not, with these two characters, Dickens painted for his vast Victorian audience a picture of the very same recovery philosophy that consumers, mental health reformers, and policy makers are getting excited about today. The Copperfield example serves to remind us, lest we all get carried away, that peer support is in its purest form when it is a simple, real relationship of mutual and reciprocal aid.

Fast forward to the current mental health literature on peer support and consumer providers. Much has been written and hypothesized about these subjects, and more recent research discussed in this article will hopefully bring financial support for peer support into the mental health system in Ontario.

An excellent definition of peer support by Mead, Hilton and Curtis describes it as:

[A] system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another’s situation empathically through the shared experience of emotional and psychological pain ... a deep, holistic understanding based on mutual experience where people are able to “be” with each other without the constraints of traditional (expert/patient) relationships ... as trust ... builds, both people are able to respectfully challenge each other when they find themselves in conflict. This allows members of the peer community to try out new behaviours with one another and move beyond previously held self-concepts built on disability and diagnosis.

Much of the literature describes research projects that have shown time and time again that consumer-provided services or peer support projects have been associated with a number of benefits to consumers and to the system: reduced symptoms, reduced use of emergency services, reduced hospital admissions and days, increased functioning, increased insight, feelings of empowerment, recovery, hope and quality of life, and cost savings. Meanwhile, consumer literature argues that peer support, in order to be effective and real, must stay in the domain of the consumers, in the community, and that we should be very cautious about modeling peer support after professionalized services. Adopting a service-provision mentality will only keep people playing the role of mental patient or client, and create a relationship that is incompatible with the principles of self-help.

Others argue that the case for peer support has been built upon inconclusive research results. They find most of the available research lacking due to flaws in the design: small study populations, lack of control groups for comparison purposes, lack of randomness in field trials, and confounding the effect of consumer-provided services with that of enhancing professional services. Because most of the projects relied on volunteer peer providers, they predict that those which claim a cost saving will likely (when the time comes that consumer providers are rightfully paid a competitive wage) prove no less costly than non-consumer delivered services. Some call for more collaborative research and participatory action research.

A more recent three-year research project now nearing completion may satisfy these concerns. “Therapeutic Relationships: From Hospital to Community” and its earlier pilot project, “Bridges to Discharge,” tested a new transitional model of discharge which involves a two-pronged approach. Hospital staff “bridged” newly discharged patients until they established working relationships with community service providers, while consumer/survivor groups, at the same time but quite independently, provided them with one-on-one peer support “buddies” who also committed to up to a year of contact. This study cannot be criticized for lacking control groups or having small numbers of people. It involved 390 participants from 26 participating wards of three psychiatric hospitals. The wards were divided into 13 similar pairs based on their treatment focus, staffing, and average length of stay. From each pair, one was randomly selected to provide the new “intervention,” while its counterpart served as the “control” ward. A total of 17
consumer/survivor groups were involved, of whom eleven were funded through a Trillium Ontario grant. Their task was to recruit, screen, and train peer support volunteers, match them with people referred to the consumer group by the “intervention” wards, support them in their peer activity, provide recognition for their efforts, and report statistical and qualitative information from them back to the research team.

Nor can this study be accused of confounding the effect of the consumer-provided support with the non-consumer-provided support. The consumer groups involved included some totally autonomous CSIs with their own Ministry of Health funding, and some consumer groups that were attached to non-consumer-run transfer payment agencies in mental health service provision. Aside from some training in how to use the statistical report forms, and some occasional education on different types of research, the consumer groups were not supervised by the research team in the area of how to do peer support. A peer training manual had been independently developed by Mental Health Rights Coalition of Hamilton for the first pilot project in the early 1990s and another was developed by CanVoice, the lead transfer payment agency for the consumer group Trillium fund. These provided bases for each consumer/survivor group to develop its own peer support training program. The Trillium fund provided for, among other things, the hiring of part-time peer support coordinators for the duration of the project. The consumer groups held quarterly or semi-annual conferences where they shared experiences, training techniques, and compared organizational stories.

The one-year results are exciting. Discharges from the intervention or Transitional Discharge Model (TDM) wards were able to occur sooner because of the supports in place while people awaited hookup with community-based service. This resulted in shorter stays on these wards, giving a cost savings of $12.2 million in the first year. Participants who received the TDM reported improved functioning and better quality of life in terms of social relations. The greatest improvement was seen in a “lonely” subgroup of people (26% of the total group), who upon enrollment had described their social relationships as neutral or unsatisfactory. This group used $20,300 less per person in hospital/ER services than the group receiving usual discharge care. Qualitative findings showed that both groups found contact with professionals, medication, and support with finances helpful, and both groups identified that talking to someone was important. However, the TDM group was able to articulate what specific issues they needed help with, which suggests they gained more insight and were further along in their recovery.

The researchers found that the best results were obtained when both the hospital staff bridging and the peer support were provided.

The implications are that partnerships between consumer groups and professional mental health services can yield improved care and cost savings, and that the TDM is most effective when targeted at individuals who perceive themselves to be lonely. The researchers call for ongoing funding of peer support programs to continue offering this service, and point out that the cost savings in providing the TDM for just one lonely person per year would pay for a part-time peer support coordinator in each organization.

As the project and the grant funding which supported these positions come to a close within a month of this writing, the consumer groups involved are facing several dilemmas.

The project brought some unexpected benefits to the consumer groups as well. Being able to offer the peer training to all of our staff, whether they are cleaners, clerical people, or program facilitators, has enhanced the quality of their working relationships with members. Being able to train a number of our members as peer volunteers has provided a good pool of eligible candidates when positions came available in our own organizations. In Hamilton, to make use of these people and provide more job opportunities, one Ministry-funded position was split in order to provide four 5-hour peer support positions with a 15-hour supervisor; this team offers peer support on demand to our general membership who do not have the benefit of being research participants. These four peer worker positions earn just enough to supplement ODSP incomes and buttress the self-esteem of the individuals who come in and out of these positions. All of the organizations have found it challenging to retain volunteers, sometimes due to relapse-and-recovery phases, but in many cases, the training and volunteering has given people the confidence to risk returning to former jobs and studies or take up new ones.

Another phenomenon has arisen since the dissemination of the one-year study results, which is encouraging but nevertheless presents a few challenges. Hospitals and medical-model community agencies are taking notice. Service provider agencies in some of our regions are hiring our volunteers and our Connections coordinators away from us. As one ACT team doctor expressed it, nothing changes attitudes and ways of talking faster than having that consumer peer support worker sitting at the team table every day. Hospitals and medical model agencies are approaching us asking for our training manuals so that they can train their own peer support teams. The focus is on using peer volunteers, not on paying competitive or even minimum wages. In one community, the local hospital even set up a street-level storefront “peer support” service, manned by nurses, to compete against the consumer/survivor group. If imitation is the sincerest form of flattery, some of the medical service providers are intent on becoming very flattering indeed.

Having saved the hospitals a whopping $12.2 million, the consumer groups now look forward to the end of March 2003 with hope and also with fear. Logically, we should be able to assume that the Ministry Implementation Task
Force will have recommended spending in the area of transitional discharge and peer support. Logically, we should assume that the policy makers in the bureaucracy will find that recommendation valid. Then, the message will have to go to the elected officials.

Will anything be lost in the translation? Is it safe to assume that this evidence-based, cost-saving, best-practicing, recovery-facilitating, collaborative model will lead to increased core funding to consumer groups? Or, will someone, somewhere, in the good old tradition of bureaucracy and politics, decide to direct funding into creating better asylums complete with extra funding for peer support programs?

If that happens, consumer groups may as well all go write our memoirs, or fly kites.

For those who have not read *David Copperfield*, Mr. Dick does eventually prove the power of his mind, as Aunt Betsey knew he would, when he carries out what we today would call an intervention, and helps a married couple acknowledge and resolve a strain on their relationship. Thus, the supported peer becomes a supporter himself. Grassroots. As it should be.

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3 Available from: URL: http://www.mastertexts.com/Dickens_Charles/American_Notes/Chapter0004.htm

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**PEER SUPPORT WORKER IN THE EARLY YEARS OF ACTT: NOW AND IN THE UPCOMING YEARS**

Frank MacPherson *

I was first hired as a peer support worker back in 1991 for the Assertive Community Rehabilitation Program (ACRP) on Bank Street in Ottawa. I think a lot of the nurses and social workers, as well as my co-workers, were very skeptical of my abilities as a worker. There were a lot of Doubting Thomas’s on the roster. Often I would get assignments that other people didn’t want.

I did have a few supporters who were very good allies in my endeavours as a peer support worker with ACRP. Some of my co-workers had been my nurses when I was on the wards at the Brockville Psychiatric Hospital.

I kept struggling with assignments that others did not want. I became something of a trouble-shooter to help a lot of the undesirables. I lasted 1⅓ years, and then was ousted for reasons unknown to me. To this day I still don’t know the real reason. I was told it was union problems or something like that.

I didn’t question it. But one person who believed in me and still does to this day is Dr. Hugh Lafave. We fought
tooth and nail to keep me there, but even his efforts
were not enough. I moved on with the help of Dr.
Lafave and went to work at Canadian Mental Health
Association.

Currently I'm working with the Assertive Community
Treatment Team at Pinecrest-Queensway Health
Centre. Things have improved a little bit, but I think
once you have been labelled mentally ill you can
never shed it. It follows you wherever you go, like a
plague. Anyway, it is a little better than it was. I still
get the doubts occasionally, but not as often. The
people I work with now didn't know me in my other
life, like some of my co-workers before, so that makes
it a little easier. I guess some of this might be my
perception, but I do know when I am being treated
differently than others on the roster.

I still get different assignments at times when there
are crucial things to do that need to be handled by
somebody more proficient in the finer points of the
treatment team. They don't send me to see clients I am
not able to do on call. It's not in the job description of
peer support worker, whereas everybody else does it. I
think sometimes I am patronized by some of my cohorts,
but again I can't complain because it is better. And I think
I am very fortunate to have a job with the ACT Team.

As far as the future goes, I think a person (consumer)
who has the abilities and the confidence to make a
difference and can advocate well for him or herself and
also for the cause will do well in this type of work.

These days, I think society and people such as doctors,
social workers, and nurses are learning to give people with
mental illness more respect and more credit for being able
to do things that regular people can do. They are giving
patients more chances than in the past.

I think the peer support worker position has nowhere to
go but up.

*Frank MacPherson has been a peer support worker for Pinecrest-Queensway for two years.

MENTAL HEALTH ACT SECTION 80:
FIGHTING FOR PATIENTS' RIGHTS

Sandra Keith *

One of the most significant rights infringements and
restrictions of personal freedom occurs when the
state detains someone in a mental health facility
against his or her will. The powers of the state are
paramount and in order to afford protection to
individuals, mental health legislation has a series of
checks and balances that serves as a rights protection
mechanism. One of the checks and balances in the
system is that when an individual's legal status is
changed, a rights adviser must be notified promptly,
the individual receives rights advice and is advised of
the right to retain and instruct counsel and to apply
for Legal Aid. The individual is also advised that
should he or she wish to challenge the finding by the
doctor, there is a right to apply for a hearing before
the Consent and Capacity Board, an independent
quasi-judicial tribunal. In order to extend further
rights protections, the Board must begin the hearing
within seven days. This is in recognition that when
the state is holding a person against his or her will,
due process rights are triggered, including the right to
have the case heard as soon as possible so that the
period of detention isn't any longer than it would have
to be, if the individual were successful in getting the
certificate revoked.

When working in Ontario, doctors must provide care
and treatment against the backdrop of mental health
legislation that regulates all changes in an individual's
legal status. The Mental Health Act has a penalty
provision enshrined in it, although the Ministry of Health
and Long-Term Care does not appear to enforce its own
legislation. I am almost certain that they have not
provided training to Provincial Offences Officers
regarding Section 80, nor how to apply the legislation.
However, as I have become aware, many doctors are
unaware of the penalty provisions and the justice system
seems unclear when this section of the law should be
applied. There appears to be a misunderstanding of the
significance of having one's rights violated, with the
system failing to respond in a way that is very
disempowering for the individual.

The Mental Health Act, Section 80, states that “every
person who contravenes any provision of this Act or the
regulations is guilty of an offence and on conviction is
liable to a fine of not more than $25,000.” However, trying
to get the mental health system and the justice system to
respond to the violation of an individual's rights is near
impossible. It seems that the system judges individuals
with a mental health history as not being capable of
discerning when their rights have been violated, or they
believe that standing up for their rights is part of their
“illness,” and then there is a reluctance to lay charges
against a regulated health professional. It is curious that
no doctor, to my knowledge, has ever been charged under
this section. It seems that the police would be more comfortable if the individual simply made a complaint to the regulatory college of the profession and declined to exercise his or her rights under the law.

When I was first admitted to hospital I was placed on a Form 3 (Certificate of Involuntary Admission) by my doctor and provided with rights advice as required under the Mental Health Act. My Form 3 was set to expire while my regular doctor was away on vacation and as a result, the doctor providing coverage for her would have to make a decision as to my legal status within the facility. On the morning that this decision was to be made I asked nursing staff several times if I could speak to the doctor. I was assured that they knew where I was and that when the doctor arrived I could speak to her. I knew that the doctor would have to either allow me to become a voluntary patient or speak to her. I knew that the doctor would have to either allow me to become a voluntary patient or continue my status as an involuntary patient.

However, the doctor who was providing coverage decided that she would complete a Form 4 (Certificate of Renewal), thus continuing my involuntary status for 30 days. The doctor had never met or spoken to me, had never assessed me and had not met her obligation in the law to “observe and examine” before completing the Form 4. I was given a notice in writing (Form 30) by nursing staff when I returned to the unit at lunchtime and the nurse advised me that the doctor had completed the Form 4. The very fact that she completed the form without ever meeting me or talking to me was a clear violation of my rights under the law.

By completing the form the doctor was giving the state permission to continue holding me against my will and by not assessing me violated my due process rights that are enshrined in the legislation. To add insult to injury, using this illegal Form 4, the doctor had me reported as a “missing person” and sent the police to my home to pick me up and return me to the hospital. The doctor had no right to choose this course of action given that the form was illegal. As a result of her actions, I now have noted on my police record that I had “contact with the police.” If I ever need to get a police record check done or a vulnerable person screening form this “contact with the police” will be noted on the form provided by the police. This is a serious consequence and could potentially inhibit my ability to pursue employment or volunteer opportunities. Doctors fail to realize that whenever the police are involved, it gets recorded as “contact with the police.”

It must be noted that the hospital administrator immediately understood the significance of the rights violation that occurred and he attempted to take corrective action. He wrote to the local police department asking that they remove all notations of “contact with the police,” given that the form was illegal. The administrator became my advocate at a systemic level in order to address the wrong that I suffered. Upon discovering the actions of the doctor, the hospital conducted an internal review to see what could have been done differently and to review the actions of the doctor. I am not clear about what really happened as part of this review as I was not involved in any way, nor was my input sought. This is somewhat troubling for a hospital that purports to provide client-centred care and is affiliated with an academic institution of excellence. I was not asked for a written submission, not asked how they could address the violation of my rights or what outcome I was seeking. I'm not even sure if they reprimanded the doctor for violating my rights. I suspect that the whole purpose of the review was to “mitigate liability” for the hospital and to perhaps look at practice issues of this specific doctor.

I decided to approach the Justice of the Peace in hopes that I could lay Section 80 charges privately against the doctor for violating my rights. I met with the Justice of the Peace and provided all of the documentation that I had accumulated, including a letter from the doctor that stated that “she apologizes for the invalid Form 4” and that the form had been completed in my “best interest.” However, the doctor failed to acknowledge that what would have been in my best interest was for her to have complied with the law and allowed me the rights protection mechanisms enshrined in the law. After meeting with the Justice I received a letter a few days later stating that the Justice found “insufficient grounds to issue process to compel the accused person to appear in Court.” I was puzzled by this response, given that I had provided the Justice with a copy of the letter from the doctor acknowledging that my rights had been violated. It is curious that even a signed confession was “insufficient” and it made me wonder why I was denied access to justice and having the matter heard by the Court. This was only the beginning of what would be a long and tedious process, but one which I will pursue until the end.

Since my efforts with the Justice of the Peace were futile, I decided to approach the police, following consultation with a lawyer and the Psychiatric Patient Advocate Office (PPAO). Again, I was frustrated by the lack of response from the police and their apparent lack of awareness of Section 80 of the Mental Health Act. It became clear that these charges were “uncommon” and this was perhaps the first time that a patient was asking the police to lay a Section 80 charge against a doctor. Since it was unfamiliar territory for everyone involved, there was quite a learning curve to overcome. Unfortunately for me, I would need to become the teacher.

Initially, the police decided that they could not lay such a charge and instead wrote me a letter redirecting me to the Ministry of Health and Long-Term Care for them to lay the charge on my behalf. I found this odd, given that the Mental Health Act contained penalty provisions for rights violations, yet I was unable to access the provisions enshrined in the law. It appeared that the police would not investigate the matter further or lay the charge. Not being discouraged by this, I wrote back to the police asking them to re-open the investigation and to again consider laying charges against the doctor for violating my...
rights. After a protracted period of silence I was encouraged one day to learn that they were going to assign the case for investigation.

The investigation process was very thorough and the police treated me with dignity and respect and not as a “patient.” They appeared to understand the impact of the rights violation on me and the significance of the actions of the doctor. However, I had to write to them to remind them that the limitation period in the Mental Health Act is six months and my time to have charges laid was running out. The limitation period for mental health matters must be examined and extended, as six months is just too short a time period. Finally, the police did lay the charge, but just before the limitation period was to expire. I would later learn in court that the detective laid the proper charge, but when the charge sheet was drafted someone took it upon himself to change the section number under which the doctor was to be charged. The Section 80 charge should have referred to Section 20(1)(5), which states that the “attending physician shall not complete a certificate of involuntary admission or a certificate of renewal unless, after he or she has examined the patient…” Instead, the clerk who prepared the charge used the wording of Section 15, which did not apply in my case as it refers to physicians’ responsibilities in relation to an Application for Psychiatric Assessment (Form 1). It was devastating to learn in court, after five appearances and many months later, that the matter would be dismissed due to this technicality and as such the case was never heard on its merits.

While I was pursuing the Section 80 charge through the court system I simultaneously made a complaint to the College of Physicians and Surgeons. This required me to make my complaint in writing and to provide detailed documentation. During the process I spoke with the PPAO about the disclosure of my clinical record to both the College and the police, as I was concerned about giving “blanket consent” to access my record and my life. It was suggested that on the Form 14 (Consent to the Disclosure, Transmittal or Examination of a Clinical Record) I could specify what I wanted to release, although the Form does not indicate this. The Ministry of Health and Long-Term Care should revise the Form 14 to allow a client to specify what information they consent to disclose and include an expiry date. The whole issue of disclosure of the clinical record in these types of proceedings needs to be examined.

The police department was very good about the entire matter of disclosure and narrowed down what they wanted access to, which I did not object to. It is my opinion that they should ask for as little information as possible and only if it relates directly to the proceedings.

The complaints process at the College of Physicians and Surgeons was protracted and my complaint was not dealt with, in my opinion, in a timely matter. It even included two staff from the College coming to my home to talk to me about my complaint and to try to convince me that I should drop the complaint because it would be “my word against the doctor’s,” as she had failed to document anything in my chart. I was horrified that I would be coerced in such a fashion, as I thought that the College was there to protect me and to investigate complaints in a fair and impartial manner. Thank goodness I had had the foresight to have someone present for this meeting who could verify the discussion and the actions of the CPSO staff.

After the meeting I immediately wrote to the College advising them that I would not withdraw my complaint as they had suggested but if they wanted the complaint to “disappear” then they would need to do that on their own motion as I planned to proceed with the complaint. I was sure that they would be as shocked as I was that the doctor had failed to document her activities in my clinical record. Finally, the Complaints Committee reviewed my complaint and in my opinion rendered an inadequate and incomplete discipline decision. Not only did they get the gender of the doctor wrong, they failed to mention that the doctor had been charged for violating my rights and that it had proceeded to court. There were several other errors or omissions in the decision and I knew immediately that I needed to apply to the Health Professions Appeal and Review Board to have them hear my dissatisfaction with the College Complaints Committee decision.

The Health Professions Appeal and Review Board heard my case almost two years after I first approached the police to lay the charges. Following my appeal of the College of Physician and Surgeons Complaint Committee decision I was notified that the Board would hold a hearing. I felt that this was my opportunity to have my concerns addressed, but I was surprised to learn that the hearing would be held in Toronto. For those of us who receive only Ontario Disability Support Plan benefits this is definitely a barrier to participation due to the cost of lodging, transportation, and meals to be able to attend the hearing in person. Any complaint process that replicates power imbalances and perpetuates inequities is not really serious about having individuals involved in the process. The Board did not at any time indicate that they would provide financial assistance so that I could attend the hearing in person and participate fully. I felt that this would have addressed the power imbalance of the doctor being present at the hearing with legal counsel. I was instead advised that I could join by teleconference. However, this was not confirmed until the day before the hearing, and only after the intervention of the PPAO.

My attendance by teleconference set up an inequity in the process, as the Board members were in the same room as the doctor and her lawyer and I was just a voice on the telephone. If complaint processes are to be fair and equitable, then all parties should have the same access to resources to be able to attend the hearing, even if this means that the Board has to provide funding to the party who is economically disadvantaged. Until such provisions...
become part of a fair and equitable process, patients will not have the same access to the process as the doctor whom they are making the complaint about. The doctor may have insurance funding to cover the cost of the lawyer, access to resources provided by the facility where they practise, and earnings that will allow them the best representation possible. I was also surprised that the College of Physicians and Surgeons did not have anyone present to answer questions or to participate in the process, although they had been invited to attend.

Members of the Health Professions Appeal and Review Board were very respectful throughout the hearing and took great lengths to make sure that I understood the process, the steps that they could take to redress my concerns, and in explaining when I could expect to receive a decision from them. I was told that they would render a decision within 90 days and although this seems like an eternity, I can wait, as I have already been pursuing this matter for more than two years and will follow it through until the end.

In conclusion, if patients’ rights are to be respected in Ontario, then ongoing education and training regarding mental health legislation must be available to doctors, police, Justices of the Peace, families, and patients. It is also essential that self-regulating Colleges be disbanded and a more accountable system that protects patients be put in place. Complaint processes must be reviewed to remove systemic bias and barriers to full participation and address inequities in the process. If mental health reform is to be successful then the entire system must adopt a “patient first” philosophy where the rights and entitlements of patients are not only respected but promoted. Patients must have a greater but equal voice in mental health service delivery and in holding doctors to account for their actions.

I am still learning from this experience and it is not over yet. At the end of it all I will know that I have had an impact on patients’ rights and entitlements and will have sent a message to every doctor in Ontario. The message will be clear, you must obey the law like any other member of the community and failure to do so will have serious consequences as you will be held accountable for your actions in a court of law. I will have accomplished my primary objective if no other patient in Ontario has to experience what I had to endure as a result of the actions of a doctor who chose to disobey the law. This is perhaps a message of hope and empowerment for every patient in the mental health system in Ontario. You can exercise your rights and you can hold doctors accountable.

*Sandra Keith, a consumer-survivor from London was the first to have Section 80 charges laid against a doctor for violating the Mental Health Act. She has developed a keen interest in promoting patients’ rights in Ontario as a result of this experience.