

VISIONS

BC Partners for
Mental Health and
Addictions Information

BC's Mental Health and Addictions Journal

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STIGMA *and* Discrimination



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bc partners

Seven provincial mental health and addictions agencies are working together in a collective known as the BC Partners for Mental Health and Addictions Information. We represent the Anxiety Disorders Association of BC, Awareness and Networking around Disordered Eating, British Columbia Schizophrenia Society, Canadian Mental Health Association's BC Division, Centre for Addictions Research of BC, FORCE Society for Kids' Mental Health Care, and the Mood Disorders Association of BC. Our reason for coming together is that we recognize that a number of groups need to have access to accurate, standard and timely information on mental health, mental disorders and addictions, including information on evidence-based services, supports and self-management.

visions

Published quarterly, *Visions* is a nationally award-winning journal which provides a forum for the voices of people living with a mental disorder or substance use problem, their family and friends, and service providers in BC. *Visions* is written by and for people who have used mental health or addictions services (also known as consumers), family and friends, mental health and addictions service providers, providers from various other sectors, and leaders and decision-makers in the field. It creates a place where many perspectives on mental health and addictions issues can be heard. To that end, we invite readers' comments and concerns regarding the articles and opinions expressed in this journal.

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it's been over 40 years since Erving Goffman wrote the pre-eminent resource, *Stigma and the Management of Spoiled Identity*. And while some inroads have been made for some diagnoses, it seems that others have filled the void. A mother of a son with schizophrenia once told me that borderline personality disorder is "the new schizophrenia." This she saw as a result of better understanding of schizophrenia. This is not, however, to say that people with schizophrenia do not still experience stigma.

In a recent conversation with a colleague, the issue of stigma versus discrimination came up. It is interesting to note that talk of *stigma* seems restricted now to issues of mental illness and addictions. In other social and health movements, *discrimination* is the word that is used. The difference here is that protection against discrimination is enshrined in the Canadian Charter of Rights and Freedoms. Stigma is not.

The articles in this edition of *Visions* talk of the many forms stigma take—societal, interpersonal, internal. And in some sense, this is preaching to the choir. As readers of this issue, we are already likely aware of the negative, often destructive impact of stigma on the lives of persons with mental illness and/or addictions. What we need to do is to share this issue with our communities, both familial and extended. As one article acknowledges, it is direct contact with a person with any of these diagnoses that makes the biggest difference.

There is a very interesting structural issue that I want to acknowledge. In putting together this issue, we had an abundance of personal and familial stories, stories from service providers and 'professionals' about what stigma looks like. Where there is a lack, and this may be our problem in defeating stigma, is in programs and services created specifically to address stigma.

Stigma will only cease to exist when people are valued for who they are, when they have educated and understanding social relations, and when we all begin to understand that self-stigma allows other-stigma to run rampant. If we think, "I'm glad that I have this diagnosis and not that one," then we are just reproducing the same problem. To battle this, we need to look deep inside and challenge our beliefs about what mental health, mental illness and addiction are. Let's hope we don't have to do another issue in 40 years to talk about the impact of stigma.

Christina Martens

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subscriptions and advertising

If you have personal experience with mental health or substance use problems as a consumer of services or as a family member, or provide mental health or addictions services in the public or voluntary sector, and you reside in BC, you are entitled to receive *Visions* free of charge (one free copy per agency address). You may also be receiving *Visions* as a member of one of the seven provincial agencies that make up the BC Partners. For all others, subscriptions are \$25 (Cdn.) for four issues. Back issues are \$7 for hard copies, or are freely available from our website at www.heretohelp.bc.ca/publications. Contact us to inquire about receiving, writing for, or advertising in the journal. Advertising rates and deadlines are also online.

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Sticks and Stones, Policies and Words...

A look at prejudice and discrimination in the field of mental illness and addictions

Sarah Hamid-Balma and Corrine Arthur



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Corrine is board President of From Grief to Action (FGTA). As a relative of an amazingly resilient recovering substance user and mental health consumer, she regularly receives lessons in humility, compassion and the need for increased public awareness. Through FGTA, Corrine promotes addiction as a public health issue to assist in breaking through prevailing stigmas

In many human rights circles, the last 50 years has been an era of increasing (albeit imperfect) tolerance. Those of us working in the field of mental health and addictions have seen change—from mysticizing, warehousing and criminalizing to medicalizing and psychologizing. We have moved people out of mental hospitals and into assisted living units; we have found that a range of treatment options and social supports help people recover like never before; we have spoken of addiction as an illness, not a moral issue.

But there's still the language—addict, mentally ill, schizophrenic, psycho, junkie—personless, labelling language that, even today, is so hard to shake off.

And why? A person cannot choose their race or gender, or reverse a physical disability; behaviour, however, is different. There is an expectation that a person should be in control of their behaviour, thoughts and feelings. And though the experts have argued for, and proclaimed victory in, having mental illness and addiction viewed as health issues, for many people it remains an issue of poor self-control and character flaw.

“What if he falls off the wagon?” “What if he acts strangely?” “What if she becomes violent?” These are not health concerns; they are judgements based on stereotypes, media depictions, and lay assumptions of causality that are embedded in our culture. “Come on, pull up your socks.” “Stop trying to get attention.” “Just say no.” “If you just got a job and got off the system...”

What it is and what it does

The mental health and addictions movements have historically always talked of *stigma*. According to the father of stigma theory, Erving Goffman, stigma is the situation of an individual being excluded from full social acceptance because of a trait that marks them as different from the so-called ‘normal’ majority. This difference then elicits some form of discrimination from the community, such as punishment, restriction of rights, ridicule and/or social rejection.¹

For the ancient Greeks, stigma referred to visible marks on the body that were branded on ‘undesirables’—slaves, criminals and traitors. Although nowadays people with mental illness and/or addictions are not tattooed upon diagnosis, the feeling is not altogether different; the brand is just invisible.

Throughout their history and up to the present day, mental health and substance use problems have been

seen as sins, crimes, behavioural problems, diseases, or some combination of these. Despite the changing frame, the perception has basically remained the same: the person is, at worst, irreparable; at best, only capable of temporary recovery through strict adherence to “the program,” “the steps,” “the medication”...

People with mental illnesses and/or addictions are among the most devalued of all people with disabilities—and by extension, friends, family and professional care providers also face a kind of ‘stigma by association.’ A major US nationwide survey of mental health consumers found that almost 80% of survey respondents had overheard people making hurtful or offensive comments, with more than a quarter often being told to lower their expectations in life.²

But the effects of discrimination go far beyond dirty looks and name-calling. Users of mental health or addictions services are denied basic rights of citizenship, encountering both subtle and blatant discrimination when accessing housing, employment, income assistance, higher education, insurance, parenting rights, immigration status and even recreational opportunities. They are often viewed as second-class citizens by the communities and neighbours they wish to live among and befriend, by the physical health care and criminal justice systems, media, mental health and addictions professionals, other service users, and even their own friends. Rejection from social supports, resources and institutions has a significant impact on a person's self-sufficiency, recovery and overall quality of life.

The case has been made³ that, due to discrimination, mental health and addictions systems are chronically under-funded—particularly when measured against the toll these conditions take on families, workplaces, and the health care and criminal justice systems.

Why prejudice is so hard to give up...

There are three main theories⁴ as to why stigma processes develop against any minority group. Each of these is at work against people with mental illnesses or addictions:

- stigmas justify current social injustices (e.g., the belief that people with mental illness were inferior justified sterilizing them)
- stigmas meet basic self-serving psychological needs (e.g., ‘I feel better about myself when I compare

myself to addicts or the mentally ill’)

- stigmas are efficient mental shortcuts that allow people to quickly generate impressions and expectations of someone based on their membership in a stereotyped group (e.g., ‘If I encounter someone with mental illness or an addiction, I’ll know what to expect’)

The public wants to conceive of sickness or unusual behaviour as occurring with reason; otherwise, life is reduced to a game of chance. Therefore, people are viewed as extensions of their conditions, so we can separate ‘them’ from ‘us.’ Though the stereotypes attached to diagnoses and substances may differ, the myths driving the stereotypes are the same: people with mental illness and addictions are violent, unpredictable with poor social skills, incapable of recovery, and to blame for their conditions.⁵ They should be hospitalized or locked up; they are worthy of help, but the public shouldn’t have to see them.

On the index of fear and stigma, mental illness and addiction cluster with sexually-transmitted diseases, epilepsy and leprosy:⁶ three conditions that have historically induced great fear in people. These are *not* the diseases modern-day telethons are made of. As Susan Sontag wrote, “It seems that societies need to have one illness, which becomes identified with evil, and attaches blame to its ‘victims’... any disease that is treated as a mystery and acutely enough feared...”⁷ Though she was writing about AIDS, the concept easily applies to mental illness and addictions.

But there is also hope found in Sontag’s words. Over time, stigmas are malleable. They can be created (drinking and driving, smoking) and reduced (cancer, AIDS). By learning from other campaigns against ignorance, there will hopefully come a time for mental health and addictions when searching for the right language will be irrelevant—when the *people* will have superseded their labels and symptoms and behaviours.

Researchers have argued that people with physical disabilities have not found stigma a useful concept because *stigma* puts the focus on the ‘branded’ person, while *prejudice* and *discrimination* put the onus where it belongs: on the individuals and institutions that practise it. Why should our movement be any different from other human rights movements? As researcher Liz Sayce says, “It’s not as if we talk about the ‘stigma of being black’—no, we talk of racism.”⁸ The adoption of a social approach that links disability, human/civil rights, mental illness and addictions with empowerment, participation and human dignity is key.

And yet, there is hope. Cultures vary in their levels of prejudice toward mental illness. For example, schizophrenia has a better outcome in developing nations because of greater community acceptance.⁹ So we need to be open to doing innovative research and learning the lessons from people’s experiences. Some of the articles in this issue of *Visions* may be a step toward that end. ■

I just finished reading my first issue of *Visions*. It was such a good and interesting thing to read and had so many perspectives and details to learn about. Being a 16 year-old boy who’s experienced a lot, I really believe *Visions* would help a lot of my peers with violence and drug issues. I think teenagehood is a lot more violent and dangerous than it was for my father’s generation. I’ve seen so much teen violence and drug abuse and overdosings that this journal really did spit the truth on this matter. This journal really did impress me, and—let’s face it—not much does impress a 16-year-old guy. Keep it up.

—Dustin White
Vancouver, BC

Although the last two issues of *Visions* focused on gender—first *Women*, then *Men*—after twenty-five years of clinical observations in my practice, I don’t see a lot of differences between men and women, in general. In fact, it’s unusual for me to see differences rather than similarities. And the truth is that men and women are each such heterogenous groups. We have to remember that. I see more differences when you introduce socioeconomic status. When it comes to certain kinds of behaviours, upper class men and upper class women are more similar than, say, upper class men and working class men. And that’s certainly true when you introduce a third variable like ethnicity. So the gender distinctions are probably much less apparent compared to other variables. *Visions* might do well to explore class and ethnicity as themes of future volumes.

—Marty Klein, PhD
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we want your feedback!

If you have a comment about something you’ve read in Visions that you’d like to share, please email us at bcpartners@heretohelp.bc.ca with ‘Visions Letter’ in the subject line. Or fax us at 604-688-3236. Or mail your letter to the address on page 3. Letters should be no longer than 300 words and may be edited for length and/or clarity. Please include your name and city of residence. All letters are read. Your likelihood of being published will depend on the number of submissions we receive.

footnotes

1. Goffman, E. (1963). *Stigma: The management of spoiled identity*. Harmondsworth, UK: Penguin.
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Stigma and Discrimination in Canada

What we have learned so far



Senator Michael Kirby

Senator Kirby is Chairman of the Standing Senate Committee on Social Affairs, Science and Technology. The committee has been engaged in studying various aspects of Canada's health care system since 1999

In February 2003, the Standing Senate Committee on Social Affairs, Science and Technology (SSCSAST) launched the first comprehensive review of the state of mental health and addiction services in Canada. The committee is in the process of preparing its final report, which will contain a detailed set of recommendations for restructuring and enhancing the delivery of mental health and addiction services in this country.

The committee is deeply committed to this study, not only because reform is essential, but also because the majority of us have had firsthand experience of the impact of these conditions. In fact, it was only once we had begun our review of the mental health and addiction services in Canada that we realized we had never talked with each other about the impact mental illness has had on our own families. This was in stark contrast to how open we had previously been with each other about physical health problems.

The issue of stigma and discrimination has already featured prominently in the three background reports on mental health, mental illness and addiction in Canada that the SSCSAST released last November. In those reports, we examined in some detail

the phenomena of stigma and discrimination and what can be done to curtail them.

We also realized, however, that we needed to reach out even more widely. Therefore, following the release of the background reports, we conducted the first of two phases of Web-based or 'e' consultation with Canadians. More than 500 people replied to a questionnaire posted on the committee's website, almost all of whom had experienced, or knew of someone who had experienced, some form of stigma or discrimination because of mental illness or addiction.

Respondents (officially referred to as *witnesses*) told us of discrimination in relation to employment, education and the justice system, as well as from health professionals. They spoke of the difficulties they encountered in finding safe, affordable housing, and in obtaining disability, life or medical insurance. We were profoundly moved by their candour and their insight.

The second phase of e-consultation, which took place between April and June, has allowed us to gauge even further the experiences that consumers, families, service providers and concerned Canadians have had with mental illness and addiction services in Canada. During this

phase, participants were able to provide specific advice to the committee on how to help strengthen mental health and addictions services in Canada.

Moreover, the SSCSAST has undertaken public hearings that will take it to every province and territory. As well, a number of special topic meetings, such as the Children's Mental Health Roundtable that was held in May, have allowed the committee to meet with advocates, consumers, psychologists, psychiatrists and educators to discuss in detail the issues relating to specific areas.

We have learned an enormous amount from the input we have received thus far. We now know that it is possible for millions of Canadians who are living with a mental disorder or addiction to live meaningful and productive lives. But we also know that for this to become a reality, action is required to deal with stigma and discrimination.

The stubborn persistence of stigma and discrimination is very disconcerting. These phenomena are clearly deeply rooted and have a profound effect on people's lives. One witness, Pat Capponi, an author, advocate and consumer, put it this way:

"A chronic mental patient is just that in the eyes of many. We are not entitled to be full human beings behind that

label, not expected to have basic personalities that mirror those in the greater population, good and bad and everything in between. A schizophrenic is a schizophrenic, and every action is attributed to that disease and not to the underlying nature of the individual."

People across Canada have also highlighted the negative way in which mental illness and addiction are often portrayed in the media, and have insisted that the media could play an important role in changing attitudes about mental illness and addiction in our society.

Many witnesses have recommended that we need a national campaign to help reduce the widespread occurrence of stigma and discrimination. They have pointed to the critical importance of educating people about mental illness and addiction in order to reduce stigma and discrimination and enable people to gain timely access to needed services and supports.

In concluding, let me insist on one thing that has become clear to us: in order for any of the recommendations we make in our final report to be implemented, it will be necessary for Canadians from coast to coast to coast to hold governments' feet to the fire. We believe that together we can make a difference. ■

Mental Illness and Human Rights

Twenty years has passed since the proclamation of Section 15 of the *Canadian Charter of Rights and Freedoms*,¹ guaranteeing legal equality to all Canadians, including those with mental disabilities. While society as a whole may still have a long way to go before people with mental illnesses are treated with the level of respect and dignity they deserve, our human rights laws have helped us understand stigmas associated with mental illnesses and have helped set rules that restructure employment and service relationships with the ultimate goal of inclusivity.

Defining mental disability

For people with psychiatric disabilities, it is important to know that all human rights decisions that apply to other protected groups, such as race, sex, and so on, also apply to them. In a case called *Gibbs v. Battlefords and District Co-operative* (1996), the Supreme Court of Canada ruled that an insurance company's policy of providing long-term disability benefits to the age of 65 for those with physical disabilities, but for only two years to those with mental disabilities unless they were institutionalized, constituted discrimination. The ruling specified that all groups protected in the human rights legislation must receive equal treatment.²

Although mental disability is included as a protected ground in the *BC Human Rights Code*, it is not defined in our legislation.³ Therefore, it is necessary to turn to other jurisdictions and to the existing case law for definitions. One of the most comprehensive statutory definitions is that found in the *Saskatchewan Human Rights Code*; Section 2(1) defines disability and specifically includes reference to "mental disorder."⁴

The following test, taken from *The Law of Human Rights in Canada: Practice and Procedure*, has been ap-

proved and applied in many human rights jurisdictions.⁵ The test says that a mental condition should be considered a disability for human rights protections where it meets all the following criteria: 1) it prevents the person from performing significant functions that can be performed by most people; 2) it is ongoing in nature; and 3) it is beyond the person's control.

The courts have determined that alcohol and drug addiction constitute a mental disability for the purposes of human rights legislation as well. A stress-related disorder may—but still will not necessarily—amount to a disability. It is a factual question as to the impact on the individual's capacity to function. In many cases, stress may signal—or even mask—a larger mental disorder.

Accommodations and standards

The first step towards inclusivity was the development of the concept of reasonable accommodation. As an equality concept, accommodation seeks to build inclusive environments that respect differences and rights in a diverse society. As a process, accommodation seeks to resolve conflicts by balancing rights and interests. The goal of accommodation is to enable the full and equitable participation of all members in society. Today, the concept of accommodation is better known by the term 'duty to accommodate' which is the legal phrase arising out of human rights legislation and case law in Canada.

In the case of the *University of British Columbia v. Berg* (1993), the Supreme Court of Canada upheld the right to accommodation when it found the university had discriminated against the complainant by providing her with limited service because she had bipolar disorder.⁶ Prior to the adoption of Section 15 of the *Charter*, employers were able to design occupational

Terri Kennedy and Susan O'Donnell

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publicly funded human rights clinic

The BC Human Rights Coalition and the Community Legal Assistance Society jointly operate a publicly funded human rights clinic. The clinic provides initial and summary advice regarding human rights issues, as well as assistance in pursuing a complaint under the *BC Human Rights Code*. Full representation, provided by advocates and lawyers who specialize in human rights law, is available to those that have lodged a complaint with the BC Human Rights Tribunal. This clinic service is available province-wide at no cost to individuals. Whether you decide to file a human rights complaint or simply want some help or suggestions with issues related to your situation, you can call the BC Human Rights Coalition for information and assistance: (604) 689-8474 in Vancouver or toll-free at 1-877-689-8474

For specific information on the complaint and hearing process, please see our Guides and Information Sheets section of www.bchrt.bc.ca

requirements that effectively excluded people with disabilities.

Balanced against the duty to accommodate is the notion of *bona fide occupational requirement*, or the standard one needs to meet in order to reasonably perform a job, or receive a service such as obtaining a driver's licence. The Supreme Court of Canada has ruled that standards in service and employment must meet a three-part test: the standard must have a connection to the work to be performed; the employer or service must have an honest belief that the standard is necessary for the work to be performed; and the standard must be one of reasonableness: i.e. the employee can do the work reasonably well. In addition, this court has stated that an employer must show it is impossible

to accommodate an employee with a disability before it is appropriate to end the employment relationship.³

Attitudes a step behind

While these concepts and definitions are moving things forward on the road to equality, negative stereotypes and attitudes continue to interfere with judgment around dealing with people with mental disabilities.

A case we settled recently serves as a typical example of how lack of understanding and poor judgement can manifest as discrimination in the workplace. Our client had re-entered the workforce after an extended absence due to bipolar disorder. He had an outstanding performance record and had no problems meeting job requirements or standards in his new position. Unfortunately, his co-workers perceived some of his behavioural traits as 'weird' and expressed a collective fear to management that his illness would likely prevent him from meeting agreed-upon sales targets. Management, thinking they would boost the morale of others, fired our client. When the employers were asked at mediation whether they allowed racist or sexist concerns to influence hiring or firing decisions, they were quick to realize how their judgement had been influenced by nothing more than negative stereotypes and fears around mental illness. Management accepted responsibility for the discrimination, and as part of the settlement, agreed to educate themselves and their workforce on working with people with disabilities.⁸

Accommodation balancing act

Beyond settlements, numerous decisions from courts, tribunals and labour arbitrators continue to send strong signals to employers indicating that those with mental illnesses are to be accorded the same right to an accommodation as those with physical disabilities. Recent cases are frequently about fine-tuning the balance between all parties' rights and obligations with regards to the accommodation process. Perhaps the most controversial of these is the *Gordy v. Oak Bay Marina* (2004) decision.⁹

This case involved a situation where a fishing guide was terminated from his position at Oak Bay Marina after entering a manic phase of his illness, bipolar disorder. Oak Bay Marina argued that assuming the safety risk of continuing to employ the guide would amount to undue hardship. The BC Human Rights Tribunal disagreed, noting that the employer had no accurate information about bipolar disorder or the likelihood of a relapse.

footnotes

1. *Constitution Act, 1982* [en. by the Canada Act 1982 (UK), c. 11, s. I], pt. 1 (Canadian Charter of Rights and Freedoms). Retrieved June 23, 2005, from laws.justice.gc.ca/en/charter.

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6. *University of British Columbia v. Berg* (1993), 2 SCR 353, 18 CHRR D/3.

7. *British Columbia (Public Service Employee Relations Commission) v. British Columbia Government and Service Employees' Union (BCGSEU)* (1999), 35 CHRR D/257 (SCC); *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)* (2000), 36 CHRR D/129 (SCC).

8. This is an example of a typical case. It has been settled recently, and as part of the agreement, the parties cannot be named.

9. *Gordy v. Oak Bay Marina, dba "Painter's Lodge"* (No. 2) (2004), BCHRT 225.

frequently asked questions

What is Discrimination?

Discrimination is when a person is treated unfairly, harassed or denied something because of the group they belong to, or because they have a certain characteristic. Under the BC Human Rights Code, it is against the law to discriminate against someone because of any one or more of the following characteristics (these characteristics are called protected grounds):

- race (including colour, ancestry or place of origin)
- political or religious beliefs
- marital or family status (including being married or single, being a parent, or simply who you're related to)
- physical or mental disability
- sex (being female, male or transgendered; pregnancy; breastfeeding in public)
- sexual orientation (being lesbian, gay, heterosexual or bisexual)
- age (where a person is between 19 and 65 years of age)
- a criminal record unrelated to their employment

When am I protected from discrimination and harassment?

You are protected from discrimination and harassment when you're:

- at work
- applying for a job
- attending school or some other educational institution
- looking for a place to live
- renting or buying property
- wanting to access a service or buy a product that is available to the public

Under the Code, the BC Human Rights Tribunal is responsible for accepting, mediating, resolving and adjudicating complaints of discrimination. Publicly funded clinic programs have been established to provide assistance and representation to individuals involved in complaints, and the Ministry of the Attorney General is responsible for developing and conducting education programs.

(source for this sidebar item: Mahil, H. (2001). *Mental Illness and Human Rights. Visions: BC's Mental Health Journal*, 1(13), 44-45).

Oak Bay Marina appealed the decision to the Supreme Court of BC, which set aside the tribunal's decision, finding that the tribunal had erred when it failed to consider the personal observations of two Marina managers. The BC Court of Appeal upheld this decision, agreeing that Oak Bay Marina was entitled to rely on the personal observations of its employees with respect to the Mr. Gordy's condition. The court referred the case back to the tribunal for reconsideration.

After all this, the BC Human Rights Tribunal came back to its initial decision: it agreed that the company's knowledge of Mr. Gordy's condition "justified a concern" and could form part of a risk assessment, but that the duty to accommodate required Oak Bay Marina to undergo a full assessment, which included educating itself about bipolar disorder in general, and the risk of relapse in particular, before being able to properly assess the risk.

Because accommodation is an individual right, it often comes into conflict with management policies and programs that are designed with a 'one-size-fits-all' approach. There is a lot of case law around attendance-management programs that adversely affect workers with mental illnesses, who may require more time away from work to attend to their disability. Equally challenging are labour arbitrations that seek to balance the rights of parties when disciplinary measures appear unfair and inequitable given that conduct may be symptomatic of a specific mental health condition.

Although the outcome of each claim rests on a unique set of facts, there is a growing recognition that a one-size-fits-all system and structure is not appropriate given the diversity of today's workforce. There is also a growing recognition and acceptance that accommodation is a multi-party process.

To avoid pitfalls, it is important that employees keep their employers properly informed about their medical condition and accommodation requirements, and it is equally important that employers engage in individualized assessment in order to reach the most appropriate accommodation.

A workplace rule or practice that conflicts with an individual's right to be free from discrimination must be modified or adjusted without affecting the employer's right to a productive workforce. Where capabilities are restricted by a disability, increasing permitted time off or restructuring certain job components may be required to allow the disabled person to apply their skills and abilities on an even playing field while making a contribution to the workforce.

One challenge for human rights law is to continue to move beyond the concept of "freedom from discrimination." Today, many of the decisions coming from our courts and tribunals in relation to mental disabilities speak to a "right to equality"; a right that is positive, proactive and implies a high standard on our institutions, workplaces and services to design and deliver appropriate systems, rather than relying on the affected individuals to fight for equality case by case. A right to equality in 2005 should be an expectation, not a surprise. ■

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Demystifying the Role of the DSM

Diagnosis with dignity

Sarah Hamid-Balma

Sarah is one of the Guest Editors for this issue of Visions

**Interviewed:
Joe Solanto, PhD**

Dr. Solanto is a therapist, consultant, and clinical supervisor and educator in private practice. For more than 30 years he has trained educators and mental health professionals in therapeutic responses to critical incidents and psychological trauma. In addition to training clinicians in diagnostic assessment and treatment-planning processes for the Justice Institute of BC, Joe teaches courses in workplace wellness, restorative justice approaches, and adventure-based counselling. Before moving to BC, he spent 18 years as a school psychologist and seven as the director of a mental health outpatient treatment centre in New York. He currently lives in Victoria, BC

Anyone who's ever been diagnosed with a mental illness, knows someone who has, or has done the diagnosing themselves knows that the *Diagnostic and Statistical Manual of Mental Disorders*¹ (known as the *DSM*, or the *DSM-IV-TR* to reflect the latest edition) can play an important part in shaping a person's illness identity. Since 1952, the *DSM* has been the psychiatrist's bible for assessment guidance. It is a powerful tool that can both encourage (through labelling) and discourage (through normalizing) prejudice and discrimination.

To learn more about the complexities of the *DSM*, I interviewed Dr. Joe Solanto, a psychotherapist and educator in private practice, based in Victoria. Dr. Solanto teaches clinician groups how to understand and responsibly use the *DSM* system at the Justice Institute of BC. His course offerings include two levels of a workshop called Everything You Ever Wanted to Know about the *DSM-IV-TR*. This, and a similar course for child and youth assessments, are geared for professional gatekeepers, such as school personnel and various mental health practitioner groups. Members of these groups may not have clinical backgrounds in the *DSM*, but often have to make provisional diagnoses. During the last 13

years, Solanto has delivered these courses on the *DSM* to more than 500 participants throughout BC.

"The course content tries to present the *DSM* system in a balanced way that not only increases understanding, but also increases the likelihood that it won't be misused," says Solanto. After two intensive days of groundwork, participants review case studies and use the *DSM* system to come up with a multi-axis diagnosis.²

While mental health consumers are not the target audience for the course, Solanto says that in nearly every session, someone invariably volunteers that they are participating out of personal interest because of a mental health diagnosis. "They'll often express their feelings of what that's done for or against them. Sometimes the learning for the group is that the person was disadvantaged by the system. And sometimes people acknowledge that it was helpful to them; that when they finally arrived at a diagnosis, it helped put them on a path of healing that they may have not been on otherwise."

Solanto approaches the curriculum in a very sensitive, people-centred way and encourages participants to appreciate the potential helpfulness as well as the limitations of the diagnostic system.

"We have to accept that any system that tries to categorize or classify is going to be limited by a whole number of factors," says Solanto. "One of those factors is that people just don't appear in black-and-white form the way that diagnoses appear; people are much more complex. And assessment doesn't have the accuracy and specificity of x-rays or lab study, so there's lots of room for subjective judgements and error. Inherent in the *DSM* system is forcing the clinician to make choices. A diagnostic category might emphasize some symptoms and under-recognize others. So, in the effort to decide on a term, you're often missing as much as you're addressing. Even an accurate diagnosis is like a snapshot of someone: true for that moment, but not the full picture of his or her life."

The person using the *DSM* tool is just as important in the equation, says Solanto. "It's been my experience that there are some excellent clinicians out there who have the necessary clinical and interpersonal skills, a thorough understanding of diagnoses and the full range of treatment options, as well as awareness of community resources; the *DSM* in their hands is really a guide to help them direct their diagnostic think-

ing. In the end, it's their clinical judgement that's most important. But I've also encountered diagnosticians who may not have the same ability to establish rapport, to have the sensitivity or the cultural awareness, or to acknowledge the social, political or legal contexts of the client's life. When you consider people outside of the contexts of their real lives, it's questionable how useful that information is going to be for them."

"The process, from start to finish, is loaded with potential pitfalls and it's only with tremendous sensitivity, awareness and caution that one can do the least amount of harm," he says. This advice is particularly important with the more controversial or problematic categories—problematic in diagnosis, treatment and, often, community prejudices.

"There've always been a few diagnoses that have had pejorative effects: in recent times, borderline personality disorder is probably number one on that list. In many cases, it still can be a kind of fatal diagnosis," notes Solanto. "In my experience, the underlying probability of early childhood trauma has not been fully appreciated. When understood in that light, it leads to a more sensitive understanding of behaviours and, therefore, the person."

Naming and renaming has been a historical feature of the *DSM* system. The term *personality disorders* is just one of a number of recently appearing psychiatric names—and it has not always served people well. In Solanto's view, simply changing the term for a previously-stigmatizing condition does not mean that the old prejudice does not attach itself to the new term. When Solanto worked in the New York school system, and *mental retardation* was the term of the day, the kids were called "retards" by their classmates. When the term was reframed to developmental disabilities, the problem didn't disappear; peers just called the affected kids "DDs." The tone of ridicule was the same.

Children in particular have had to face the recent parade of newer diagnoses, such as conduct disorder, oppositional defiant disorder, and attention-deficit hyperactivity disorder (ADHD).

"We have to ask ourselves: are these diagnoses real clinical entities or are they a by-product of many different factors: social, political, familial, cultural, legal? ADHD is one of those that has more behind it than the individual child's neurological development," says Solanto. ADHD is culturally localized, since European and other nations do not recognize ADHD as a prevalent clinical condition. ADHD is one of many disorders in the *DSM* that has been heavily linked to a Western-based pharmaceutical influence and so has been culturally redefined through marketing.

"That's another pitfall of the diagnostic system: that so much of it is linked to the biomedical model," says Solanto. "Clearly, I have seen people's lives saved and transformed with the help of psychotropic medication. But I think the strong influence of the biomedical/pharmaceutical model has conditioned mental health clinicians to be thinking down that track from the outset. That has to colour how you think about the person, and whether you consider all the other possible causes, or treatment options."

"Certainly, some people have found freedom in announcing their mental health diagnosis, that they're on medication, that it's changed their life. Rather than stigmatizing them, it has empowered them and, paradoxically, has allowed them to feel less abnormal. However, it's more common that psychiatric medications are associated with 'craziness' and disability. The medications come with the potential benefits, but also with that cloud over them."

As attitudes—toward medication, other treatments, or mental illness in general—are culturally defined and reinforced, Solanto's course curriculum includes attention to Appendix I of the *DSM*, which encourages clinicians to conduct a cultural assessment during diagnosis. They are encouraged to ask questions such as: Are there any cultural factors that might better explain the person's behaviour, or that should be taken into account in treatment planning? What is the potential

The DSM is 900 pages long and defines more than 300 mental disorders. Sales of DSM-IV (1994) and DSM-IV-TR (2000) have sold more than one and a half million copies to date.³

impact of cultural differences between the diagnostician and the client?

"We have to remember that it is a very culturally bound system and the *DSM* itself emphasizes repeatedly—more heavily in later editions—that it represents a North American cultural world view. In this part of the world, when clinicians are working within very diverse communities, if we are to use a culturally bound system like the *DSM*, we have to think of how to address the cultural relevancies of it in some way that keeps a caution alive throughout."

Cultural assessments are one way clinicians are encouraged to think of their own assumptions and acknowledge their own prejudices and world views and how that informs and complicates the diagnostic process.

"It all starts with self-examination," says Solanto. "Mental health clinicians, all along the spectrum, can benefit from a regular check on their attitudes and beliefs, because even if you didn't come into the work with negative ones, these may develop over time. You can become particularly cynical and distant as a self-protective measure. I think it takes constant vigilance, a lot of peer-sharing, ongoing professional training, and good super-

vision. All sorts of folks are drawn to this work, and if you're already inclined to not be very engaged or compassionate, you'll find lots of ways in this field to express all of that."

Despite all these cautions, Solanto's encounters with practitioners around BC have been heartening. He says, "Mostly though, I find the dominant attitude of the folks who take my course is that they come very humbly to the task of doing an assessment. I've been quite impressed with the level of sensitivity, caution and compassion that they convey in talking about their clients. Even when we do the more clinical case studies, the discussion most often goes toward the human side of the story and what would really be helpful for this client."

And, clients are gaining power in therapeutic situations. This adds a beneficial balance to the *DSM* therapeutic equation and to the potential stigmatizing effects of a diagnosis. "It is great these days," says Solanto, "that the ordinary person is getting more knowledgeable—talking to others, reading the books, coming to the meetings, and getting on websites—and, as a result, asking more questions. The empowerment that comes with that is half of the healing." ■

footnotes

1. American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.
2. A multi-axis diagnosis looks at various factors affecting symptoms. In the *DSM* there are five major axes: 1) clinical disorders, 2) personality disorders and developmental disability, 3) general medical conditions, 4) psychosocial and environmental problems, and 5) global assessment of functioning.
3. Spiegel, A. (2005, January 3). The dictionary of disorder. *The New Yorker*, 56-63.

On the Borderline

Carmen Lenihan

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For more information about BPD, please contact the Borderline Personality Disorder Association, 504 Sutherland Avenue, Kelowna BC V1Y 5X1, Phone: (250) 717-3562, or e-mail us at bpda@shaw.ca

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* lists a set of criteria used to diagnose borderline personality disorder (BPD). These criteria include a frantic effort to avoid real or imagined abandonment, patterns of intense and unstable relationships, unstable self-image, impulsivity, and a chronic feeling of emptiness.¹

Once a diagnosis of BPD has been made, it brings with it a set of consequences. Some may be good, some not so good. At the Borderline Personality Disorder Association in Kelowna, we requested feedback from individuals living with BPD and their family to better understand what it is like to have the disorder or to care about someone who does. Below is what we discovered.

In what way has the diagnosis been helpful?

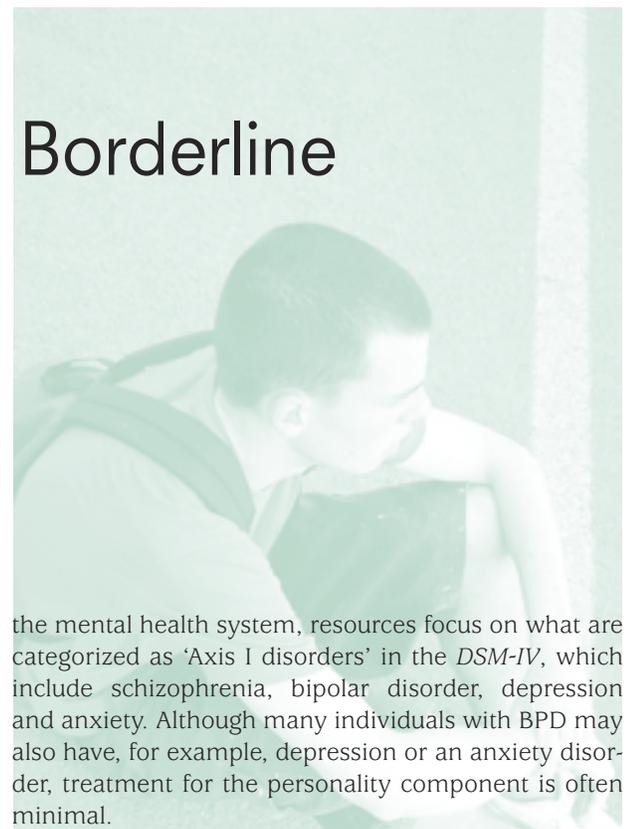
General consensus was that it can be a relief to know “there is a name for it.” Once something is identified, it’s easier to get information and begin to get help. One individual with BPD commented that not knowing what was wrong was difficult, and from that perspective, the diagnosis was a relief. Sadly, that is pretty much where the positive comments ended.

In what way has the diagnosis been hurtful?

Using the word *borderline* in the name is itself stigmatizing. One individual commented that the name implies not knowing how to categorize someone to make them fit societal norms, so they are on the borderline—but on the borderline of what?

Another frustration is lack of understanding in the general community. One individual diagnosed with BPD was asked by a prospective landlord if she becomes violent. This individual feels it may actually be better to lie and make up a different disability when asked why she is on a fixed income. So, not only are her options to find housing extremely limited, but she now feels she has to lie in order to be accepted. This kind of stigma is often reinforced by the media, which portrays people with mental illness as violent or who are to be feared. While there is a little less stigma and discrimination around some disorders that have received more media attention in terms of education, public awareness of BPD is still in its infancy.

The lack of resources available for people with BPD is also hurtful. As previously mentioned, it can be a relief to get a diagnosis so that help can be sought. So often, however, there is not enough help. Even within



the mental health system, resources focus on what are categorized as ‘Axis I disorders’ in the *DSM-IV*, which include schizophrenia, bipolar disorder, depression and anxiety. Although many individuals with BPD may also have, for example, depression or an anxiety disorder, treatment for the personality component is often minimal.

As someone living with BPD, what would you most like people to understand?

The societal fear around BPD and mental illness in general needs to be addressed. It can be very isolating living with BPD because of misconceptions, a lack of professional support, and because, by virtue of having BPD, relationships are challenging.

Living with BPD is a struggle that doesn’t need to be compounded by stigmatization and discrimination. People’s misunderstanding and false perceptions lead to more hurt and de-humanization. As one person said, “Please don’t treat us like you don’t know what to do with us.”

As a family member, what would you most like to share?

Family members indicated that educating themselves about the disorder was very important. As well, getting a good support system in place can make a tremendous difference. Find a support group, or start one if necessary.

What is needed?

As previously mentioned, support for BPD seems limited. Additional research into BPD is necessary, and more therapists must be trained to meet all the needs presented by individuals diagnosed with this disorder. Outside of the professional realm, educating the general community is crucial. Stigma and discrimination will not lessen if people continue to have no information, are misinformed, or buy into fearful myths. ■

footnote

1. American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

The Stigma of Addiction Project

Turning voices into action

Society tends to stigmatize behaviours that are seen as different and less desirable than what is considered the acceptable norm. Substance use, and moods and behaviours often associated with mental illness, clearly fall into this category. The stigma (prejudice and discrimination) associated with substance use and mental health problems creates barriers to accessing necessary care and support for individuals and their families.

Stigma refers to negative ways in which society views people with addiction and mental health problems. But if we were talking about racism, sexism, homophobia or ageism, we'd use the words prejudice and discrimination instead.

A few years ago, the Stigma of Addiction project of the Centre for Addiction and Mental Health (CAMH) set out to identify strategies for communicating anti-stigma messages to various audiences. Literature reviews and the voices of people directly affected by stigma informed this process.

Through interviews and focus groups, we heard from people with past or current substance use problems, as well as from family members and service providers across Ontario. They talked to us about stigma and stereotypes, and suggested ways to reduce prejudice and discrimination.

Stigma and stereotypes

Here are some of the responses we heard when we asked, "What does stigma mean to you?"

- Negative judgement
- Judgement based on one aspect of a person's life
- Long-lasting labels
- Disgrace
- Embarrassment and shame
- Something you are not proud of and want to hide
- Being treated differently from the rest of society
- Hating yourself

Who is stigmatized most?

When we asked which group of people with substance use problems are stigmatized the most, answers fell into the following categories:

- People who use illegal drugs (especially injectable drugs; crack and heroin)

- People who take methadone
- People who use any drug a lot
- Women (especially if they are pregnant or have kids)
- People of lower socio-economic status
- Older adults or younger people
- Aboriginal people

How does stigma affect people?

Stigma affects every aspect of a person's life, in ways that are impossible to measure. The following impacts on life were mentioned most often:

- Violation of human rights (e.g., being treated with less consideration and respect when seeking medical care and housing)
- Lack of employment (losing jobs and difficulty getting jobs if substance use problems are known)
- Negative feelings about themselves (internalizing the negative beliefs of others)
- Avoiding services (e.g., fear of disrespectful treatment)
- Continuing substance use (to cope with other people's negative attitudes and their own feelings)

Suggestions for reducing stigma

Three themes emerged about ways to reduce stigma:

- Educate people** (including students, health care and other professionals, as well as the general public)
 - Highlight the reasons people develop problems with substance use
 - Address media biases and inaccuracies
 - Portray people with substance use problems as human beings
- Personalize substance use problems**
 - Have people who have experienced substance use problems and the related prejudice and discrimination speak about it
 - Use well-known spokespeople to raise awareness that substance use problems can affect anyone
 - Show that people with substance use problems come from a variety of backgrounds
- Tell positive stories**
 - Show the positive face of people with substance use problems rather than the negative (e.g., ways in which individuals contribute to society)

Taking what we learned into the community

In the next phase of this project, we presented the results of our research to the community. Examples of some of our awareness-raising events included presentations at conferences, community coalitions, and to

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Ellie works in Education and Health Promotion at CAMH, conducting workshops in the community to raise awareness of the impact stigma has on individuals with co-occurring substance use and mental health problems

addiction and mental health agencies; and a forum for the general public.

As an immediate response to the suggestions for reducing stigma, we made an effort to have someone who has been affected by the stigma related to substance use problems participate as a co-presenter at the events. These were golden opportunities to “educate,” “personalize” and “tell positive stories.”

A toolkit for action

The collective voice of the community led to another project, resulting in a practical resource to actively address the stigma related to co-occurring substance use and mental health problems. *Beyond the Label: An Educational Kit to Promote Awareness and Understanding of the Impact of Stigma on People Living with Concurrent Mental Health and Substance Use Problems* is a free resource, offering activities that emphasize the impact of

attitudes and beliefs on people with concurrent mental health and substance use problems; highlight facts and dispel myths; present positive stories and solution-focused approaches; and support addiction and mental health workers in their efforts to reduce stigma, prejudice and discrimination

Beyond the Label focuses on hurtful language which leads to prejudice and discrimination. How people are labelled can actually affect the way we feel about them and how they feel about themselves. Negative stereotypes often associated with terms like “junkie,” “drunk” or “psycho” eclipse other stories of a person’s life—their strengths, successes and possibilities.

The last word

Stigma is not just about hurting someone’s feelings. Stigma is about prejudice, discrimination and violating a person’s human rights. ■

Seniors, Alcohol and Stigma

Just imagine . . .



Seeing Solutions: Canadian Community Action on Seniors and Alcohol Issues, a national project funded by Health Canada (2000-2003), examined promising practices emerging in prevention and treatment. As part of this project, seniors and service providers from across Canada shared their personal experiences of stigmatization associated with drinking problems. Here are a few excerpts from the report:¹

Imagine a place where you were unable to let anyone know about the personal struggles and fears you faced in daily life. Imagine taking the risk of being shunned by your few remaining friends if you dare to let them know about your condition.

Imagine being denied affordable, appropriate housing because of stereotypes about ‘people with your problem.’

Consider the frustration of being told that you aren’t allowed to receive help in your apartment from special community services so that you could handle your condition better, and yet being told if things don’t change, you will have to move.

Imagine being reluctant to talk openly with your doctor about your condition, and your doctor being afraid to ask you. Or imagine knowing if that you did disclose, that you would be given a label that coloured the way people saw you and everything you did. If you ended up in hospital, you might be arbitrarily denied access to emergency care, treated as a ‘bed blocker.’ The pain you experienced from a broken arm might not be treated. Ageism and stigmatization can be a fatal combination.

These are a few of the real effects of misconceptions, stereotypes and stigmatization for an estimated 21,900 older

seniors in British Columbia—and more than a quarter million seniors in Canada—who experience alcohol use or prescription drug problems. Alcohol use problems affect between 6% and 10% of seniors who drink, a rate on par with other age groups. However, the issue often remains hidden until a health care, housing or service delivery crisis develops. And, because substance abuse is largely invisible, the appropriate community resources to help are often lacking.

Stigma and its effects

Ancient Greeks used the word *stigma* to refer to body marks that identified people others should avoid. Academics describe stigma as having ‘master status,’ meaning it eclipses all other aspects of the person, including their strengths, talents and abilities.

Seniors point out that stigmatization makes it unsafe for them to acknowledge personal alcohol or prescription drug abuse concerns. They are fearful of being judged by others, particularly by their peers. While having an alcohol or prescription drug problem is painful and isolating, stigma reinforces that pain and isolation many times over.

Even language commonly used by the public and service providers (like *alcoholic* or *addict*) is often highly stigmatizing. It often conjures up images of those who are ‘down-and-out,’ or who lie, manipulate and fail to live up to their responsibilities.

Stereotyping overlooks the diverse circumstances in which alcohol and drug use problems may develop. Older women may feel more social pressure and stigmatization than older men do. It’s somewhat ►

Charmaine Spencer

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Working closely with community agencies that serve seniors, she focuses on mental health, substance use and aging issues.

Charmaine was Project Coordinator for the national Seeking Solutions: Canadian Community Action on Seniors and Alcohol Issues project

Not In My Backyard

NIMBY alive and well in Vancouver

Our neighbourhood helps define us. Many of us have put a great deal of thought into where we would like to live, and once we are there, we work hard to create a living space that supports us. We all take great care in ensuring that our communities stay healthy, livable, desirable places to live.

For people recovering from a mental illness, an addiction, or both, it is well-documented that a safe, stable and supportive housing environment is an essential part of recovery. It could be argued that a strong community setting is also an essential part of the recovery process. By and large, most people with mental illness or an addiction can, with a lot of hard work, support, effective treatment and proper self-management, successfully reintegrate back into the community—sometimes after years of disconnection from it.

Sadly, these two ideals often clash when people recovering from mental illness and/or an addiction attempt to reintegrate into a community. NIMBY, the ‘Not In My Backyard’ sentiment, often rears its head, making the reintegration process even more difficult and painful.

NIMBY can be defined as the desire to keep a perceived unpleasant thing out of a community. People will generally support the need for these unpleasant things to exist, but want them located elsewhere. In most cases, these same people will claim that their beliefs don’t have anything to do with NIMBY attitudes, but everything to do with the unsuitability of recovery and reintegration services to that particular neighbourhood.

In addition to NIMBY attitudes, there are people who hold the view that a particular thing should never be built anywhere, ever. Unfortunately, these feelings

are shared by many when it comes to treating people with mental illness and addictions.

Recently Vancouver has had two instances of proposed facilities ending up in storms of controversy in their respective neighbourhoods. Each facility had been in advanced stages of planning and was seeking Vancouver City Council approval.

In the first case, the Vancouver-based Triage Emergency Services and Care Society proposed to build a 39-bed apartment building to house men and women who have a mental illness but were also recovering from a street-drug addiction. The people housed in the facility, to be located in South Vancouver at Fraser and 39th Avenue, would be in the later stages of their recovery with less risk of relapse. Over the course of several public meetings, concerned members of the community showed up, outraged that this particular facility was being located in their community.

Fear regarding mental health and addiction can usually be put to rest with some simple knowledge. Those of us personally connected with these issues need to ensure that proper information is available.

It is also clear that both Triage and the City of Vancouver needed a better plan for communicating with the community. According to a *Vancouver Sun* investigation, only 277 flyers were sent out to this dense urban community to explain the project, and only in English—neglecting that the neighbourhood is predominantly Chinese and South Asian.¹ ►



Mykle Ludvigsen

Mykle is Communications Officer at Canadian Mental Health Association, BC Division

related resources

- MacNeil, M. (2004). *NIMBY: When Affordable Housing Development Meets Community Opposition*. Calgary, AB: Housing Strategies Inc. www.sharedlearnings.org/res.cfm
- HomeComing Community Choice Coalition. (2003). *Yes, In My Back Yard: A guide for Ontario's supportive housing providers*. www.onpha.org/affordable_housing_initiatives/nimby/
- National Low Income Housing Coalition. *NIMBY Reports*. Various newsletters and reports (2000-2005) at www.nlihc.org/nimby

Seniors, Alcohol and Stigma | cont'd

acceptable for men to drink to excess, but not for women, and certainly not older women. “You are supposed to be little ladies, prim and proper,” shared one study participant. Another said, “I remember my father saying to his five daughters, ‘I don’t care how much you drink, just don’t show it.’”

Hope for the future

Seniors point out that during the past 40 years many social and health issues that used to be highly stigmatized have lost their shaming effect. One example was cancer: “In earlier generations, people did not mention the ‘C’ word.” Another participant shared: “Family matters such as divorce or

out-of-wedlock pregnancy were once considered shocking.” And children with developmental disabilities used to be hidden or institutionalized, “but that changed a lot with the Kennedy’s daughter [Rosemary] in the 1960s.” Seniors note that attitudes and beliefs have improved significantly through public education and awareness.

Active efforts to normalize these issues, as well as changes in legal systems and social structures along with positive role models, have helped to open up discussion and break down stereotypes. Older adults ask you to imagine a similar positive future for people experiencing alcohol use problems—and to help make it happen. ■

footnotes

1. McMartin, P. (2004, October 20). Maybe the NIMBY side has a point. *Vancouver Sun*, B1.
2. Ministry of Housing, Recreation and Consumer Services. (1996). *Toward More Inclusive Neighbourhoods*. Retrieved June 10, 2004, from www.mcaaws.gov.bc.ca/housing/NEIGHBOUR. See the section called "Property values unaffected by non-market housing."
3. Repper, J., Sayce, L., Strong, S. et al. (1997). *Tall Stories from the Back Yard: A survey of opposition to community mental health facilities experienced by key service providers in England and Wales* (executive summary). London: MIND.
4. Sayce, L. & Willmot, J. (1997). *Gaining Respect: A guide to preventing and tackling community opposition to mental health services*. London: MIND.
5. Reda, S. (1996). Public perceptions of former psychiatric patients in England. *Psychiatric Services*, 47, 1253-1255.

The flyer sparked fear amongst community members that this project was being imposed on them with little debate, and that obviously someone must be trying to cover something up. A fundamental rule in controversy communications: the less information put out to the public, the more suspicious the public becomes.

And instead of having a debate on the merits of the particular location for this facility, the 'debate' featured accusations that the city knew the community didn't want the facility and was trying to sneak it in the back door. It also didn't help that an unlicensed facility for former sex trade workers recovering from addictions existed in the neighbourhood that people hadn't previously known existed. The city quickly moved to shut that facility down.

anti-NIMBY strategies

*"I was more frightened of the [neighbourhood] residents at the first public meeting than I have ever been with any of the patients I have worked with"*³

Best practices rooted in lessons learnt by 98 local non-profit, housing, trusts, and voluntary organizations include the following:⁴

- supporting service users to be as involved as they want to be in planning how to prevent and deal with community opposition
- providing a contact number that people can call if they have concerns
- having facts and figures ready
- promoting partnerships between professionals, media, consumers, neighbours, even neighbours from areas who no longer oppose a project
- being prepared to listen to reasonable complaints and make changes (e.g., about the size of a facility or parking arrangements) without compromising key service issues (e.g., 24 hour access)
- if the facility is user-run, selling the idea
- never making promises that would lead to discriminatory exclusions (i.e., excluding people with criminal records or substance use problems)
- if trouble persists, working with police, media, allies and make use of criminal law if necessary
- above all, not giving up or apologizing
- being proactive and not slipping facilities in sideways where you might avoid opposition initially but also lose a pool of goodwill
- in a UK survey, neighbours suggested the following be included in an education program: practical skills on dealing with problem behaviours, understanding more about what mental illnesses and addictions actually are, available treatment services, and the importance of accepting people with mental illness and/or addictions.⁵

Then, just as the Triage controversy was winding down, Family Services of Greater Vancouver moved into the final stages of approval for a youth services centre to be built in Vancouver's downtown, across from St. Paul's Hospital. The proposed facility would integrate services for at-risk youth, which were spread throughout the Downtown and West End neighbourhoods, into one facility. The community has had serious problems with street youth for some time, and the plan would move services out of facilities in predominantly residential areas to a more commercial area conveniently located across from one of BC's largest medical centres.

Despite what appeared to be an excellent opportunity to situate these services on a centrally located, city-owned property, where they would be easier to access by at-risk youth and easier to monitor by police and other social service agencies, opposition in the surrounding area began to crop up. Notices were placed in the lobbies of apartment buildings and slipped under people's doors, inviting them to attend the public meetings to oppose the project. In some cases, building managers and property owners were encouraging tenants to turn out and oppose the project.

These hearings also revealed a fundamental need for information on mental disorders. Even though the facility was not just for people with mental illness or addiction, mental illness was one of the key points seized on by opponents to the project.

In the end, the project was revised to include a management plan, as well as the integrated youth services centre, and will go ahead. When completed, it will likely meet with the same response that greeted the Dusk to Dawn youth drop-in centre that was established across the street at St. Paul's Hospital in the early 1990s: people who live nearby will hardly notice it's there.

In most cases, the neighbourhood concerns are unfounded. Research has proven that schools are no less safe because of the nearby existence of a facility for those with mental illness and addictions, and that property values in an area do not go down (in fact, the province itself has done extensive studies on this subject with some evidence suggesting that property values can even go up, not down).²

While NIMBY reactions to projects that will benefit entire communities are difficult to deal with, and at times maddening to people who desperately need those services, they do serve a valuable purpose. The debates about them propel society to learn about the particular disorders and afflictions, become familiar with the agencies that deliver services, and give those agencies a chance to prove to skeptical members of the community that they are assets to the community. Debate provoked by NIMBY attitudes also helps agencies improve plans to mitigate fears and create effective communications strategies to combat those fears, including having service users themselves talk to concerned neighbours.

As in everything, a little education and open communication go a long way. ■

I Want a Little Respect

mental illness is very common. It's a quiet disease, however. Physically, the disability often remains unseen. It's an affliction within one's heart, mind and soul.

You must not stereotype us as 'crazy people'; you must understand that we have an illness. We must learn more about these devastating conditions. Let's not forget, mental illness plagues millions of people throughout the world. We don't deserve to be frowned upon or considered unimportant members of society.

Many of us who are afflicted with mental illness try very hard to hide ourselves from the general public, so that we are not recognized as having a disability. We don't want other people to know that we're not 'normal.' We have worn masks throughout our lives, and know which face to put on in which circumstances. We are so clever that our deception is usually never detected. Our illness and struggle is kept secret.

Fighting the ailment can leave one confused and exhausted. Physical ailments arise from the continual battle within one's self. The battle becomes unbearable, and the 'combatant' can become too weak to continue the fight.

Subconsciously, we cry for help through our actions, because often we are unable to ask for help

on our own. These actions are an automatic response to our own mental pain. There is no thought or planning; our minds no longer have control. We can usually remember our actions, but are certainly not in control of them. We are also usually unable to explain our actions, because we really don't understand them ourselves. Many people with mental illness are substance abusers—including me. We try to clear or remove the anguish by any means possible. The most common substances, in descending order, are coffee, cigarettes, alcohol, and prescription and illicit drugs. Unfortunately, many of these substances can greatly interfere with a solid treatment program.

I have respect for people with multiple sclerosis, AIDS and other medical ailments. Why should I not be respected for my medical ailment? Attitude towards the mentally ill must change—not just for our sake, but for the sake of all those who come into contact with us. Society must learn to accept the mentally ill for who they are. Education is a key to becoming a better person and to learning about others. A little understanding will go a long way to removing the stigmas and fears associated with mental illness.

I once volunteered my services to a local charity. They knew I had a mental

illness. They treated me as if I was mentally incompetent. I was given useless tasks of no importance. Even though I previously had a career in the army, where I used equipment worth hundreds of thousands of dollars, they believed I wasn't capable of the simplest tasks, such as gardening—I most certainly can pick up a shovel. They talked slowly to me, and I was never left unsupervised. This treatment made me feel inept and belittled.

I have met an incredible man, however, who has the power and authority to inform the public of life with mental illness. Vern Faulkner is the editor of the *Esquimalt News*. He listened to my story and felt that the topic of mental illness was important enough to do a two-part series. He examined the political, structural and emotional aspects of mental illness. He then ran the stories,¹ which were later picked up by other sister papers. He made a substantial effort on the behalf of the mentally ill to inform and educate the public about this ailment, and has recently been nominated for a journalism award for his efforts. He made a weighty contribution toward removing the stigma of mental illness. I have the deepest respect for him, and he also treated me with respect.

In my entire life, Vern Faulkner is the only per-

son who has treated me as a normal human being. I have been ridiculed, belittled and abandoned by friends and family. I have been accused of being lazy and of being a useless bum who should get off his butt and work. The public needs more education to help prevent the stereotyping of us as useless and lazy people. With the proper support and medical intervention, we are capable of taking care of our families, running households, working in the public sector and accomplishing our dreams and goals just like 'normal' people. We can do all of that and still have time to be tortured by an illness on top of it all!

Although my illness has caused severe challenges, my wife and her family are also incredible. They have stood by me, never wavering for a single minute. My wife has had many reasons to leave me, but her love and support has made me survive. Her incredible courage to withstand some terrible situations and to still stand by my side is remarkable.

All I want is to live a happy normal life, free from prejudice. People with mental illness want the respect that many 'normal' people take for granted. Everyone has their own 'bottom line.' I ask that you respect mine. ■

Patrick Schnerch

Patrick's first 12 years of life were normal and happy; then his world came crashing down. He lives in Victoria, with a diagnosis of manic depression

footnote

1. For his series on mental health, Vern Faulkner of the *Esquimalt News* won the Best Feature Series award (4,000 to 12,449 circulation division) in the Canadian Community Newspapers Association's Best Newspapers Competition on June 6, 2005. He was also first runner-up in the Best Feature Photo category for a photo used in this same series.

Does a Person Have to Look Sick to be Considered Sick?

Personal reflections

Kate is a Mood Disorders Association of BC member and has been a recipient of care from the mental health care system since 2004. She lives in the Lower Mainland. You can contact her at its_your_healthcare@yahoo.ca

When people, including professionals, think of mental illness, their perception may be of a person who is not taking care of themselves and their responsibilities, and whose behaviour is out of control. As true as this is for some individuals, there are also people affected by mental health conditions who do not present in that way. This does not negate the fact that there are times when treatment and intervention are clearly needed to prevent further decline in a person's functioning, regardless of how they appear externally.

How have I come to understand the difference between *looking* healthy and actually being unwell? My perception of mental illness has changed because of my own experience of it. I used to have the stereotypical idea that people with mental illness appear 'out of it,' and were identifiable by their erratic behaviour and messy appearance. I realize now that I also believed mental illness was a character weakness. My perceptions were due in part to my family's attitude towards mental illness. Several relatives have experienced depression, but within my family mental illness was considered a weakness and was treated with a 'hush-hush' attitude. Thankfully, their attitude, and mine, has changed as a result of my experience.

During the past two years my mental health has been challenged, and it's only recently that I've been

properly diagnosed. Knowing that I needed medical attention for what was occurring was not something I was pleased about, given my independent nature. But deep down I knew treatment was necessary, including the need for medication. Were it not for my general practitioner (GP) and associate and staff, I don't know where I'd be today. The treatment, un-

derstanding and proactive care I receive from these individuals is supportive beyond words. Sadly, some of my other experiences have not been as positive.

I believe that my education and external presentation has had a bearing on some professionals' misperceptions of the intervention I have needed at certain

times—I have a post-secondary education with plans to further it, have a professional career in a health care field, and have experienced other successes as well as challenges. Many professionals, it seems, have the same prejudicial ideas that I used to have about what mental illness 'looks like.' Even though I may appear okay on the outside to others, I can be significantly challenged internally and experiencing changes in my normal pattern of functioning and energy level. I can appear strong and confident, but feel unwell. Those who know me have the proper insight to understand this change. This is why, in my opinion, a person must be viewed individually and not placed into a defined category where assumptions are made solely on the category itself.

Prejudice and stigma in our society about the appearance and behaviour of the mentally ill may stem from the fact that people do not receive adequate treatment until their condition and functioning deteriorates significantly past the point where they ought to receive intervention. The prejudice can be that of the person who is ill, their family, friends and co-workers, or that of health care professionals.

The experiences I've had make me wonder if one has to be totally 'out of control' before intervention can occur. Do we have to look or act a certain way even if we are not quite at that point clinically, but instinctively know we will soon end up there without the proper treatment? Does a person have to arrive at a hospital emergency room (ER) with very little or no ability to function before they are taken seriously? What ever happened to the basic premise of listening to the patient and gathering the proper information before making an overall objective *and* subjective conclusion? Does the health care system want to prevent/limit repeated ER visits and hospital or facility stays? If so, where does proactive medical care fit into the picture?

These questions may be difficult to answer in a quick and easy way, especially with all the constraints the health care system is facing. But not taking the time to listen or over-medicating a person and sending them home from the ER, on their own because there are no inpatient or community facility beds available on that day, is not the answer. I believe these questions deserve close consideration by mental health care professionals and governments. Policy makers should also seek input from individuals who use mental health care

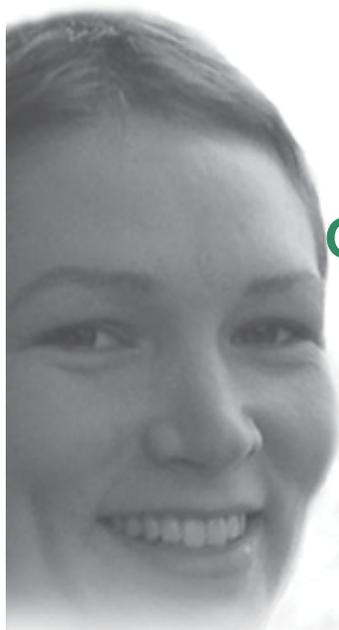


services, regardless of their background.

As a result of recent experiences at my local ER, I now have a written “Crisis Health Plan” to help me to receive consistent and unconfused treatment when I feel I have to go to the hospital. I created this plan with my GP, and it includes contact information for my physicians and details about my diagnosis, symptoms, coping skills and tolerance of medications and dosages. The plan is on file at a large community hospital where I was able to receive what I feel was appropriate care.

My condition is improving, and I’m very satisfied with the medical professionals involved in my immediate care and treatment. I also benefit from a high-quality group therapy program.

I hope that sharing my experience will help each and every one of us to take the time to reflect upon our own situation (personally or professionally) and what we can do to help all people with mental health conditions receive the best of care—regardless of their external appearance. ■



Today, I Choose Life!
On HIV, addiction and being a mom

“Wow, you’re really healthy for someone who’s had HIV for six years. Women with that die a lot faster than the men do.”

Coming from a man who has a lot of contact with recovering addicts, this ‘declaration’ took me by surprise. All hope of a casual conversation lost, I tried to present him with some actual facts about living with HIV—but to no avail. Though I try not to let ignorance affect me, I found myself feeling insulted.

One of the challenges in educating people about this virus is that our knowledge is changing and expanding on a daily basis. Something I learned two months ago may no longer be the current understanding, let alone something learned five years ago. I’ve met doctors who haven’t bothered to

update their knowledge, so it’s no surprise that many other people still base their ideas about HIV/AIDS on information taken from a 1970s news release.

I know that when I was diagnosed as HIV positive in 1999, I believed even then that I had no more than the expected seven years to live. However, at the time, I was an IV drug addict and wouldn’t have lived another year the way I was going.

HIV woke me up enough to save my life. I have accepted this path. I am not in need of pity; I don’t want anyone to be ‘sorry’ for me. I’m a strong woman who has begun walking the lifelong road to recovery. I have

nourished myself through two pregnancies in the years since testing positive for HIV and hepatitis C. I do volunteer work with addicts going through withdrawal, treating them with detoxification acupuncture, which I learned to do after I experienced how much it helped me. My two young boys are beautiful, healthy and normal, and I am just as frazzled and content as any other mother I know.

I have challenges, of course. I have adopted a ‘high raw’ whole foods diet and am doing a liver cleanse to detoxify myself from a 15-year nicotine habit kicked on March 1 of this year. I’m still on a methadone program, though my dose is low and I am tapering off. (From experience I strongly suggest that the process of tapering be done slowly, with patience and lots of support—and not before you are ready!) I feel I’ve built a solid foundation on which to live the rest of my life, but it has not been

easy, nor will it be later. With good management (diet, lifestyle and medication when needed), however, HIV positive people today can plan for a real future—beyond the standard seven years!

When I look back on my journey, one of the issues that really stands out is the deadly idea that once a woman becomes pregnant, being a *mother* will automatically replace being an *addict*. I know firsthand how the fear of having one’s children apprehended can keep mothers from reaching out for the help they need. My firstborn was taken from me when he was six months old. I took the opportunity to attend a day treatment program, and began to learn what recovery was really about. Six months later, after heartbreak and hard work, my son was placed back into my custody. This wasn’t the end of my struggle though.

One of my hopes is to help open a drop-in

K.C. Younker

K.C. is a 28-year-old mom who loves to play and to eat wild food. She lives in Saanich and the photo on this page is an actual photograph of K.C.

centre, where pregnant or mothering addicts can come access services such as peer counselling and detoxification acupuncture in a non-judgemental, non-invasive setting, regardless of their amount of clean time. I read about a similar program at a New York hospital which saw a significant reduction in the number of babies born addicted as a result.

Sometimes recovery is all about believing that you *deserve* to take those two steps forward, after having

taken one step backwards. One thing that has helped me immensely has been going into a sweat lodge. It has been necessary for me to connect with others in my community who are familiar with the cycle of addiction and loss, and the process of healing. A descendant of European ancestry, I have always felt out of place, especially in 'normal' working class circles. I have seen and experienced too much to pretend that my own well-being is all that matters,

when people are hurting and dying all the time. I get very lonely at times. Some days I think a lot about my old street family and how we were before everyone got messed up on drugs and spread out over the continent. I know that few of us survived to adulthood. Through a group of people who come together to pray in the sweat lodge, I have found quiet support and role models of great strength and wisdom. I give thanks for having met them. I also

give thanks for the support from my acupuncturist and my immediate family.

No one's path is an easy one; no one knows what will happen tomorrow. We are all here to learn, and my children have been, and will continue to be, my greatest teachers. Whenever I start to feel affected by someone else's judgements, I try to remember my own tiny glimpse of the big picture. I have been blessed, and I know who I am and where I stand. █

Navigating the Stigma of Mental Illness and Addiction

A service provider's perspective

Debbie Suian, MA, RCC

Debbie has been a therapist for over 20 years, and currently works as a concurrent disorders therapist. She is an instructor at the Justice Institute of BC and the editor of Step Softly, a publication of the Tri-Cities Mental Health Centre

These are the words of a person in recovery from mental illness and addiction. Poignant and insightful, they are words that speak to the power of stigma.

For many people in recovery, stigma is a constant companion. Mental and physical illness, poverty, trauma and isolation can make fitting into mainstream society difficult. Alcohol and drug use is frequently seen as an effective way to deal with problems that might otherwise feel overwhelming. From time to time, people ask for help. Sometimes the assistance provided is helpful, other times it is not. At any given time, there are enough people asking for help that those who slip away can easily go unnoticed, returning to lives of despair, where alcohol and drugs can be counted upon to numb feelings that never seem to go away. Sometimes, those people die. It can be said that stigma kills.

In recent years, public awareness campaigns have been launched with the aim of encouraging people to reach out for help. Although an important initiative in

“We need to educate people, even the addict, so there isn't the shame. It's so ingrained in me that it's bad to be what I am that when you don't get mad at me, I struggle with that. I don't know how many other addicts feel that way, but I bet it's lots—and their families too.”

—Person recovering from concurrent disorders

the war against stigma, what has been overlooked is the inability of resources to meet the ever-growing demand for services. Discussion of these difficulties is beyond my scope here but important to note because they take a toll on potential clients who find themselves 'deflected' elsewhere, on service providers who are seen as 'passing the buck,' and on the resource that

becomes the object of the deflection. In this context, stigma flourishes.

Stigma and discrimination do not begin with the request for help. Too often, discrimination is perpetuated by the help that is offered or is unavailable. At the systems level, there are simply not enough services to meet the needs of the people who require them. While this is not news to health care professionals, it can be distressing. Where services do exist, admission criteria are sometimes so strict they almost guarantee that those who most require help will be least likely to receive it. Discovering that treatment is unavailable—or even worse, inaccessible—can be devastating for peo-

ple who have finally come to terms with the idea that change is needed, and that help is required to make that change happen.

As an addictions therapist working in an outpatient clinic, I have frequently heard stories of the unremitting shame people feel at having to come to such a place and ask for help. As a concurrent disorders therapist, I hear similar stories of shame as people disclose the fear they feel that someone might see them entering or leaving a mental health centre. These are issues that professionals coming to work through those same health centre doors every day can easily forget. After all, “asking for help is a sign of strength,” we tell our clients, and for the most part, we act as if we believe that statement. But the twists and turns inherent in concurrent disorders treatment can wear down even the most welcoming, empathetic and hopeful of therapists when prevailing attitudes suggest that people bring the misery of addiction and mental illness upon themselves.

In spite of scientific advances into the study of mental illness and addiction, many people living with these conditions are stigmatized by the system, by service providers and, at times, by one another. For example, within addictions, it is one thing to smoke, snort, or to swallow, but it’s quite another to inject. Within the mental health system, it’s one thing to be depressed or anxious; it is quite another to be psychotic.

The power of stigma reaches a whole new level when people living with mental illness also abuse or become dependent upon substances. The treatment of co-occurring disorders is neither short term, nor straightforward. Recovery is frequently a journey into a ‘no man’s land’ of confusion, despair and isolation. It takes an incredible amount of courage on the part of an already demoralized and suffering person to travel a path laden with the possibility of further rejection and disappointment. Along the way, even the most compassionate and caring of therapists can forget the power of stigma until reminded firsthand of its sting.

Historically, the addiction and mental health systems have had strong feelings about one another. Not uncommonly, these feelings have been negative. We are, it seems, very good at identifying each other’s shortcomings and failures. In this context, stigma also flourishes. If we wish to be effective in the war against stigma, we must set aside our differences and join together in the service of helping people heal. In making the decision to work with people whom others do not value, we must guard against devaluing one another. In the same way that we loan our clients hope, we must find a way to nurture, encourage and support one another, regardless of the system from within which we work. Only by putting clients first, and working together to create a truly integrated system of care, can we make an impact on the stigmatizing events that define the daily realities of far too many of the people we serve. ■

Stigma and Suicide

Historical, Real or Perceived?

I vividly remember the weeks immediately after our treasured son’s suicide. I remember being wrapped in a cozy blanket of non-judgemental caring by friends, family, church, co-workers and the agencies working with us. I remember the compassion of RCMP Victim Services in North Vancouver as they told us of Reed’s suicide in Calgary. I remember those first long-distance phone calls to tell friends and family that Reed had died by suicide—and realizing that I needed to care for them as much they needed to care for me. I appreciated the Calgary police and the Alberta medical examiner for their gentle questioning and patience with my tears.

Not everything was perfect. Unlike other deaths, survivors¹ quickly discover that talking about a suicide brings dinner conversations to a screeching halt. But the true impact of stigma is that it keeps survivors from connecting with each other, robbing us of both “like me” support and the opportunity to band together with professionals to “make a difference.”

Sadly, it’s often the professionals working the closest to new survivors—funeral home staff, grief therapists, and other service providers whose well-

meaning comments often inadvertently perpetuate stigma. The funeral home would not let us say in the obituary that Reed had died by suicide, and they only very reluctantly included “donations to the Reed J. Ball Memorial Fund for Suicide Prevention.” Also, every book I read while struggling with ‘why’ seemed to focus on the family as the problem.

This was stigma as originally defined.² I felt like Hester in Nathaniel Hawthorne’s novel *The Scarlet Letter*, set in Puritan New England. In the book Hester is forced to wear a large scarlet ‘A’ on her clothing to announce her adultery. I felt like I walked around with a large ‘S’ on my forehead. Eleven years later, I still fight this sense of imposed guilt.

A recent study reported: “incidents were recounted of children who had lost a sibling or a parent, returning to the school environment and being subjected to harsh treatment by both teachers and fellow students. Responses ranged from that of a teacher informing a

P. Bonny Ball

Bonny is a survivor¹ of her 21-year-old son’s suicide 11 years ago. She is now Acting Vice-President and Chair of the Survivors Division, Canadian Association for Suicide Prevention. She is also Project Manager of Vancouver Suicide Survivors Coalition, a project of the Consumer Initiative Fund of Vancouver Community Mental Health Services

footnotes

1. in the suicide prevention field, “survivor” or “survivor of suicide” are terms used in reference to people who have been affected by the suicide death of a family member, friend, colleague, or client/patient

2. stigma originally meant a brand, tattoo or physical marker on individuals, a visible mark of shame



footnotes

3. Davis, C. & Hinger, B. (2005). *Assessing the needs of the survivors of suicide: A needs assessment in the Calgary Health Region (Region #3), Alberta*. Retrieved June 9, 2005, from www.calgaryhealthregion.ca/hecomm/mental/SuicidePostvention.htm

4. Ezzel, C. (2003, February). Why? The neuroscience of suicide. *Scientific American*, 288(2), 44-51.

student that her father would be going to hell because ‘suicide is a sin,’ to students ostracizing a student who lost her sibling by saying ‘stay away from her, she has suicide germs.’”³

For our family, the worst impact of stigma was not when our son died, but after his first suicide attempt. Stigma meant that we told no one. Stigma thus isolated us from the very support and information that might have made a difference then.

Following Reed’s death, the minister of our new church offered sympathy and guidance, and encouraged us to be open about his suicide. She said there had been two or three suicides over the years in that congregation and she

could see how the impact of stigma and silence had rippled down into the third generation. Our being open about Reed’s suicide might, she suggested, help these folks in their healing. At the memorial service everyone knew that Reed’s death had been a suicide. The minister spoke tenderly about Reed, giving the assurance that “God would take his hurting child home.”

This gift of non-judgemental support continued as my husband and I returned to work. Our co-workers, a typical Vancouver jumble of ethnicities and faiths, compassionately supported us no matter what their particular background taught about suicide.

In short, in the midst of trauma, we were blessed,

spared the secondary trauma of stigma and allowed to grieve appropriately. Other survivors who are open about their loss report experiences similar to ours.

But even with little overt stigma, members of our Vancouver Suicide Survivors Coalition often still internally feel historical stigma—that perceived ‘S’ on our foreheads. For last year’s World Suicide Prevention Day, we decided to ask libraries and bookstores to build a book and brochure display around our poster, but we were nervous to ask. However, we found the librarians were enthusiastic, and several shared stories of suicide in their families and among co-workers. Just making our request to the libraries helped to

tackle stigma. And we learned that the stigma we feel, that perceived ‘S,’ is sometimes just that—perceived, and not real.

The language of suicide is changing from “committed” suicide, with its connotations of sin and/or crime, as well as “completed” or “successful” suicide, to the more non-blameful, non-judgemental “died by suicide,” which finally provides appropriate and acceptable language for obituaries.

Other change is happening. Researchers are beginning to untangle the science underlying this complex issue; for example, positron emission tomography (PET) tests being researched might one day help doctors determine who among their depressed patients have the most unusual serotonin-related brain activity—a feature that has been linked to high risk of suicide.⁴

And the media is improving as an ally, tackling stigma with well-researched, informative and compassionate background articles, exploring suicide as tragedy rather than as a sin or a crime to be sensationalized.

Thus fortified, many survivors choose to stand up to stigma. We take advantage of ‘educational moments’ to talk about the suicide that has impacted us. More and more survivors are choosing to be open and are met with compassion and understanding, empowering others to also be open. As often as not, people respond with stories of suicide in their own circle. The silence is breaking. █

Living with Prejudice **An MtF perspective**

Theresa Collinge

Theresa was raised as a male, but always knew she was a girl inside. Theresa eventually reached a point where she could no longer live her life for everyone else, and began transitioning to female in 2003. She is a member of the Phoenix Centre Clubhouse in Nanaimo

There are many forms of discrimination faced by the male-to-female (MtF) transsexual, from all areas of society. There are some people who will use religion as a reason to hate us and to discriminate against us...

Most in the field still treat it as a mental condition. *Transsexualism* (renamed recently as *gender identity disorder*) is listed in the *DSM-IV-TR*, the manual that categorizes mental conditions, but I don’t feel it is a mental condition. New research is starting to look more at the biological roots of it, particularly the neurological and endocrinological (hormonal) influences. But inclusion among the list of mental illnesses adds prejudice to my life. Because that’s not how it feels; it feels very much that it is a condition that occurs in our bodies before we are born. This is not a choice we make, to live this way. And for some of us, the choice becomes dire: either to change or to take our lives...

A lot of the stigma and discrimination would stop if people could just open up their minds, use their mouths and ask us why we do this. My partner and I have found that educating others about this does help. We talk to students and anyone else who shows an interest. So, I ask: please open your minds and try to learn about us. █

to read Theresa’s full article, go to www.heretohelp.bc.ca/articles

Mental Disorders

The Result of Sin?



A few months ago, an acquaintance told me about her mother-in-law, Cynthia*, who had been found to have bipolar disorder. In her late 50s, and always having been a competent person, Cynthia had a great deal of trouble coming to terms with this. She refused to accept the diagnosis or to take the medications prescribed by her doctor. She was hospitalized several times. Failing to cope, her life—and her family’s life—was in turmoil.

The evangelical faith she followed did not encourage her in her battle. The general opinion she had grown up with was that emotional problems were an indication of not “being right with God”—the result of sin. In her mind, and in the minds of many others in her church, her illness was not a medical issue. They believed, as one author wrote, “If a person has ‘the peace of God which passeth all understanding’ (Philippians 4:7) in his life he cannot have emotional conflict. Ultimately...symptoms are spiritual problems.”¹

Cynthia’s friend from church told her that taking medications demonstrated a lack of faith. The friend advised her to throw away her pills. Not long after, Cynthia was found wandering the streets of another city, confused and

in a daze. She had to be committed to hospital against her will. To this day, she is still in denial, feeling guilt and shame.

Hearing this story saddened me deeply. Being a Christian with bipolar disorder, I know how important my faith is to my well-being and how much I need the support of a church family. I am not alone in this. And medical professionals are becoming increasingly aware of the importance of spirituality to mental health.

Some Christian writers have revealed that a large segment of those identifying themselves as Christians does indeed cling to faulty ideas and judgmental thinking, and lacks compassion towards those with mental illness. In spite of overwhelming evidence of biochemical factors in mental illnesses, many well-known, respected writers and evangelists still believe these illnesses are caused by sin and weakness of character—that is, by something that is under our control.²

The very church that preaches Christ’s unconditional love and compassion, in some instances, hurts its most needy members. Some of the dynamics contributing to this irony include:

- The fuzzy line between the psychological and the spiritual
- The fact that one often

feels an absence of hope and faith when emotionally ill

- The belief that being a Christian means you’re emotionally healthy
- The mistrust of modern medical findings
- Misinterpretation of the Bible
- The biblical concept of demonic possession
- Fear because of misunderstanding and not knowing how to help

At the same time, it’s clear to me that not all Christians stigmatize those with emotional problems. At the United Church I belonged to for 14 years, I was open about my disorder, having decided long ago that if I wanted to help end the stigma, I myself would have to stop hiding my condition. My church friends read the book and articles I wrote and became familiar with my story. In spite of this—or perhaps because of it—I was loved and accepted. I became an active member of the congregation, taking on a number of leadership roles. Only occasionally did I sense some awkwardness with people who were aware of my background but didn’t know me very well.

More recently, I began attending an evangelical church and here, too, I’ve found support. When I let my new pastor know

about my problems, he expressed a desire to learn about my disorder.

I haven’t always been a Christian. I know what it is to be ill with, and without, God in my life. But now, during crises, I’m no longer alone when it becomes difficult to hang on. I now have a spiritual lifeline—a loving God—in whom I can trust. My faith means everything to me. This is why Cynthia’s story disturbs me. Those who are in the best position to encourage her are causing more suffering.

All of society needs to become better informed about mental disorders. Yet, for members of faith communities, this is especially so because of the important part they play in the emotional care of their members. Pastors and other church leaders desperately need education about mental health issues, so they can encourage—not reject or judge—those with emotional difficulties.

And, they need to know when it’s time to help members of their pastoral community seek medical care. ■

Marja Bergen

*Marja is a writer and photographer living in Burnaby. She has written newspaper and magazine articles about mental health issues. Her book, *Riding the Roller Coaster: Living with Mood Disorders*, describes her life with bipolar disorder and the coping skills she has found helpful*

* pseudonym

footnotes

1. Solomon, C.R. (1971). *Handbook of Happiness* (p.48). Denver: Grace Fellowship Press.
2. Carlson, D.L. (1994). *Why do Christians shoot their wounded? Helping (not hurting) those with emotional difficulties*. Downers Grove, IL: InterVarsity Press.

Breakdown at Work

How I was treated when I needed long-term disability coverage

Max Danvers*

Max lives in Delta. The following is adapted from a transcript of a live interview with Max about difficulties accessing workplace disability insurance. He was interviewed for a documentary made by the Canadian Mental Health Association's BC Division. The documentary was released in February 2005 as an adjunct to a 2004 report on the same topic. To access the report and the documentary online, and to see other people's stories as well as recommendations for employees, employers and the insurance industry, see www.cmha-bc.org/research

* pseudonym

I was working for a large chemical waste company as a plant foreman and an on-site union representative. I had worked there for about seven years and had climbed the ladder well. It was the kind of job that everyone considers, these days, very secure. It paid well, I was a senior man and I had security, benefits, pension—the whole bit—but in the end, none of it helped.

I was diagnosed with depression in my early 20s, but at work I had the ability to hide it well and I held on for a long time. Every day I would go to work and hang on, and then I'd pretty much just go home and sleep. I had no energy left. As time went on, it got worse and worse. The politics and stress at the company didn't help.

I kept trying to battle my symptoms by working night and day. One day I had a meltdown. I broke down in tears and just couldn't cope with it at all anymore. They had one of the Health and Safety guys take me to the doctor.

Some of my co-workers were somewhat standoffish, some were supportive, others looked at me and thought that it was just a scam; that I was just trying to get time off—ironic since *who wants to be labelled with mental illness?*

It's interesting to me how there can be people who are so well educated and yet just can't comprehend the devastation that depression causes. There's a serious lack of understanding out there. To this day, it's a thing that I don't share with people except for close friends; even some of my family doesn't understand. Well-meaning people would like to, but they just don't have a full appreciation.

The company itself was self-insured for short-term disability, and that was for three months, then you applied for long-term disability through the private insurer. When I was off on short-term, I was told by the company to apply for long-term and to do it right away. I said no; that I wanted to come back to work.

When I did return to work, I was just thrown into the melting pot. It was basically like nothing had happened; nobody wants to talk about these things so I just went right back to assume my regular duties. Half a day later, I was shaking and sweating and in tears again. When I was taken, again, to the hospital, I realized that I had to apply for long-term coverage. That's when the whole dilemma started.

I had never before submitted a claim to the

insurer. Frankly, I didn't think that there would be any question as far as being covered. I had been diagnosed a decade or two before, and they had actually denied me group life insurance through the company *because* of my illness. And yet, when I had to go off of work, the same company denied my claim saying that I didn't have an illness; that it was just work-related stress. So it's ironic that the same company is telling me two different things.

What angers me the most about it is that I just wanted to get back to work. That's all I wanted to do. I wasn't trying to scam anybody. All I wanted was help to get back on my feet.

It was about three years after I applied and the court date was approaching that they finally had a psychiatrist come and interview me. Their own psychiatrist admitted that, had the insurer just paid the benefits to keep my family afloat while I recovered, I would have been back to work long before.

In the end, there was a settlement, but the damage was done. Basically, it was far too little too late. To this day, I'm still trying to recover from it. I lost my marriage and had to sell everything I owned just to keep my family in

the house, just to pay the bills and cover the rent. I had three children and I'd always been the supporter. A month before I went off of work, we had been pre-approved for a mortgage, we had a down payment, my credit rating was good, bills were always paid in advance. And through all of this, I lost everything. I honestly thought we were going to end up on the streets.

It's like if somebody has a cold, you don't stick them in a refrigeration unit and tell them to get better. I was down. I was down as far as you could go, and I couldn't get back up—and it wasn't for lack of trying. I did everything I could, but antidepressants alone aren't enough. The last thing anybody needs when they're down like that is more financial trouble and creditors phoning.

A stable income is important to everybody. To this day, I don't want to be rich; it doesn't matter to me to be rich whatsoever. All I want to do is pay my bills and support my family—and when that's disrupted, you feel like a failure as a father, and others view you as such. All you want to do is get better. You don't need a fight when that's going on. It's the last thing anybody needs. ■

And the Cement Cracked and Crumbled Away



There is a crack in everything. That's how the light gets in.
—Leonard Cohen

It was April: the season of rebirth. I stepped out of the hospital and into the sunlight, suddenly aware that I was no longer wearing a puke-coloured gown and disposable slippers. I was wearing the clothes I wore when I was admitted. I was a normal person wearing normal clothes and walking normally down the street. Given the unexpected and devastating storm that was my hospital stay, I clung to anything that reassured me life after hospitalization would be normal again.

The years leading up to April 2004 were marked by fear, anxiety and a drowning darkness. I began to have trouble in 1996 at the age of 14. For three years, my weight swung high and low; my eating habits were disgusting; and I ate inordinate amounts of junk food along with regular meals. I ballooned to a size 16. I had gripping anxiety attacks in the middle of the night; I flirted with suicide.

At age 17, I had so little will to live that I didn't apply to any universities, even though I knew that my Chinese parents expected no less. At home, I had built a strong and sunny exterior that belied the war raging inside me. My sister was shocked to find that I hadn't submitted any applications, and subsequently helped me with my application to the University of BC.

The next three years were marked by many new experiences, challenges and decisions. I sought help for my problems and I began to develop a sense of self-worth and empowerment. I switched from Commerce to Arts, which felt right in my heart. I joined the co-operative education program and was introduced to the professional working world. I was learning and thriving.

At the same time, I struggled with a mind-weakening and soul-crushing depression that went undiagnosed. I had no appetite. The world was tasteless, colourless, 'feel-less.' I was numb. I couldn't cry. I felt exceedingly guilty and reeked of self-loathing. Each morning I had to muster every ounce of willpower to pry

myself out of bed and go to class. I would be wiped out long before the end of the day. Insomnia haunted me. Though it was clear to me that it was getting increasingly hard to live, I managed to stay on top of school and complete four co-op work terms.

I thought that if I could just give the appearance of a happy, high-functioning student, whom people thought was well-liked, intelligent and talented, my inner hell would eventually shrink away. But it didn't. It grew tall and large, ferocious and insistent.

The more depressed I grew, the less I saw my psychologist. I began missing work. Due to escalating problems at home, I fell into a suicidal crisis and was accompanied to the emergency ward at Vancouver General Hospital (VGH) by co-op program staff. There, I saw a psychiatrist, then a social worker who connected me to the Domestic Violence Program (DVP). I had a history of physical and psychological violence at home.

Seeing a DVP social worker was helpful. After a few months of seeing this social worker regularly and my psychologist intermittently, I got marginally better. I landed a coveted, challenging summer job. Outwardly, I was doing so well. Inwardly, I continued to struggle for years with sleep and eating and mood disturbances.

Finally, a crisis counsellor encouraged me to get an assessment for depression at Student Health Services. Within days I was diagnosed with major depression and generalized anxiety disorder. I was put on medication. Easy as pie, as if they had treated many other students for the same reasons. *Then why do I feel so alone?*

The diagnoses didn't surprise me, but they were unsettling. I was ambivalent about antidepressants. I was a bad patient because I didn't take them as prescribed. I noticed improvement after about four weeks of taking medication, and was starting to feel normal again—whatever that meant. But when six months later they ceased to bring relief, I stopped taking the little white pills. And paid a heavy price.

Rosalyn

Rosalyn is a fourth-year interdisciplinary arts student in Ethnic and Intercultural Studies at the University of British Columbia. An aspiring writer and social activist, she writes about life and mental health at www.back-space.ca/lite

Rosalyn would like to give special thanks to her high school teacher Joanne for recognizing and nurturing the seed in her, and for encouraging Rosalyn to tell her story

In the fall of 2003, I left home and moved into a campus residence, then began another rapid and debilitating descent into darkness. *I thought the medication was supposed to drive this away for good!*

Again, I worked hard and studied hard despite my diminishing appetite, severe lack of sleep, and heavy heart. Over three months, I lost a quarter of my weight. I went weeks without going to classes. I was so disengaged and withdrawn that my roommates, classmates and professors hardly saw me. I barely cared. I wanted to die. But I didn't even have the energy to do that.

Then I had strange out-of-body and out-of-reality experiences that rattled my consciousness. I sensed something was going wrong with me, that I needed help. I reached out to a trusted colleague, who accompanied me to see my psychologist. The psychologist referred me to psychiatric services. The next day I found myself in an ambulance being wheeled to the Psychiatric Assessment Unit at VGH. This was in March 2004.

Words like *psychosis* and *depression* possessed me at the hospital. It was simultaneously comforting and frightening. I knew I was depressed, but I didn't know I was also psychotic. I was given medication, and for the first time in months I slept through the night.

Colleagues and co-workers visited; no friends came, because they didn't know I was hospitalized—and I didn't want them to know. When my mother came, I was cloaked in shame and guilt. I willed myself to get better as quickly as possible, even though the last thing I wanted to do was breathe.

April came and I was still alive. I was well enough to be released. Recovery is like cultivating a seed covered in cement. It needs extra nourishment, loving support and tender care. It needs sunshine, water, and rootedness to the earth. Even though covered in cement, the seed can grow *under* the cement and will break through it in time. The key is having faith that it *will*.

My recovery began in April of 2004, when I took immense pleasure in the pink and white cherry blossoms I could see from my window. My long wait for regular appointments with a psychiatrist ended, and I dutifully took the proper medications. Soon after, the

seed took root and a tiny green leaf lifted its face to the sky, and the more I nourished it, the more leaves grew. I did that by taking care of myself, managing my stress, eating well and exercising regularly, and making a commitment to get better through weekly therapy sessions with my psychiatrist. Being really sick gave me a new appreciation and gratitude for being well.

Recovery is also about grief and sadness. The most painful part of my recovery has been the aloneness, the silence, and the internalized stigma—cultural and social—of having a mental illness. Recovery has been a lonely experience for me. *If depression is so common, especially among students, why do I feel so alone?* Aside from the people who assisted me with getting help, and my employer who graciously arranged accommodations, no one else knew about my illness, my family the least.

The greatest stigma did not come from others, but from within myself. I befriended silence for a long time for fear I would be cast aside once people knew I was not 'normal.' But as Susan Rook¹ once said, "What is normal, anyway, but a cycle on your washing machine?"

I then realized that to stay silent was to feed the stigma growing inside of me, and eventually it would swallow me up. I had to break it, so that others, too, may know that they are not alone in the storm, and that help is available.

Help was not readily available to me, but when I had the energy, I persisted and found the courage to ask others to help me persist. When you have help, you have hope. Hope comes with knowing that no matter the outcome, life is blessed with meaning even in misery, and is therefore worth living.

April 2005 marked a year since I left the hospital. I am eating, exercising, writing, volunteering and engaging in life. Some days are good, some bad. The bad days help me to fully enjoy the good days.

I know that if I just keep going, keep believing that I will get better and that my life is important and meaningful, I will see more and more flowers growing, until one day, the cement that is depression will crack and crumble away. ■

footnote

1. Susan Rook is a former CNN Anchor and current advocate for addiction recovery. This quote is from her presentation "Reporting from the Front Lines of Addiction and Recovery" at the February 2005 Bottom Line Conference on Workplace Mental Illness and Addictions by the Canadian Mental Health Association's BC Division

A Place to Call Their Own

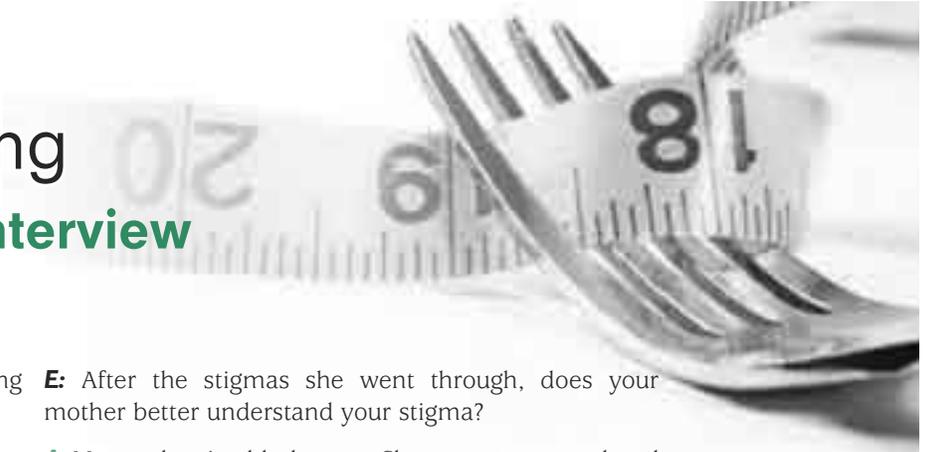
Donna Murphy

Donna is chair of the FORCE Society for Kid's Mental Health

my first impression of the psychiatric unit at our local hospital was much the same as my 17-year-old son Kelly's: we were terrified. I knew that Kelly needed to be hospitalized—he was feeling very despondent and suicidal, and had been admitted as a voluntary patient—but I wasn't so sure that this was a place for his mental well-being. "How ironic this is," I thought. "When my son is so ill, I'm afraid that the hospital may just make him worse." ...

To read Donna's full story, go to www.heretohelp.bc.ca/articles

Stigmas Surrounding Eating Disorders: Interview



Elizabeth: In the past you've hesitated about sharing your story. This time, you agreed right away. Why?

Anne: I feel I've been 'in the closet.' I know this analogy doesn't have anything to do with mental health, but I feel I suffer the same stigma as gays did in the past. We hide our 'true lives.' We have come a long way in understanding gender differences. I want to help us to come out of the closet and for the public to understand the bulimics and anorexics.

E: Do you believe other mental illnesses are better understood and more 'accepted' than eating disorders?

A: Yes. Absolutely. My personal experience has to do with my mother who suffered from depression and anxiety, when it was 'not talked about.' Many moons ago, she was prescribed tranquillizers that were 'not talked about' in our family. Later on she received therapy and took antidepressants. Today, as an older person, she can speak openly about her medication and her support systems. In fact, many of her friends have similar treatments, and so she feels safe in speaking out. This has made her stronger and more confident, and we joke about the "old days" of her "secret" pills. I think if I were to ask everyone I worked with over a week, there would be many who would come forth about suffering from depression. I think that they feel safe in talking about it. No one talks about eating disorders.

E: In your opinion, why are eating disorders—in your words—still "in the closet"?

A: On most of my attempts to 'come clean' and speak to my friends and family about my eating disorder, they turn it into me dieting. They talk about food and how I'm trying to be skinny. They don't listen. They just don't get it. It's easier to hide in the closet and stop talking to them about it. None of my family members want to know why I have had this illness.

Do you know what it's like? I go to a family function, and I get, "Oh, you are way too thin! You need meat on your bones." And, "You look pale. I better show you how to make a good meal." Everyone watches what I eat. No one asks about, or wants to listen to, the causes. It would be easier for me to say that I lose weight because I am depressed. *That* they could understand.

E: After the stigmas she went through, does your mother better understand your stigma?

A: My mother is elderly now. She cannot comprehend the concept of purging. The less she knows, the better.

E: You have shared with me what you believe to be the triggers that contributed to your eating disorders. When you've shared this with your friends and family, have they better understood your illness?

A: No. No one wants to take responsibility for my problems. They find it repulsive that I'm a bulimic. I've had a relative say that they can picture me vomiting in the bathroom, and that I should be ashamed of myself. I think she sees it as a 'spoiled kid's rebellion.'

E: You've met others with eating disorders. Do you think they feel the same way about the stigma?

A: Yes, I meet people all the time who had disordered eating and experimented with diets that went too far. But they stopped. Eating disorders are something else. I felt like I was in an AA meeting when I went to my first support group about 18 months ago. It was the best thing I have done. We could be open with each other.

I think it was best put in context when one woman in the support group—a high school teacher—said that she tried to document her need for a leave of absence due to her anorexia. When she honestly submitted her forms and supporting documents, she was urged to qualify her leave of absence as being for her 'depression,' because her colleagues and the administration would fully understand this due to classroom stress levels. She interpreted this as: if her colleagues knew she was anorexic, they would have seen her as being 'irresponsible' and 'out of control.' So she decided to stay in the closet and document her absence as depression.

E: How should we address these stigmas?

A: Time will take its course, like it did with gender issues, depression and anxiety. I've decided to train with ANAD for their community outreach presentations. After completing their program, I will be able to deliver positive body image presentations to schools, businesses and others. By doing this, time and time again, we will break down the stigma wall. ■

Elizabeth Thornton Cronin and Anne

Elizabeth Thornton Cronin is former Executive Director of Awareness and Networking Around Disordered Eating (ANAD)

Anne, now a 33-year-old high school teacher, reflects on the stigmas of having bulimia. From age 8 to 16, she was bullied by her male cousins; her scars were shown in her bulimia. Anne has not purged for 30 months and is confident in her current support systems



Adjusting Our Dreams



Karen

Karen lives in Port Alberni

** pseudonym*

Two years ago, when my son Wayne* was 16, he was a handsome, well-rounded young man, destined for a healthy and productive adulthood. He had great talent in his literary and communication abilities. He was a valued employee at a part-time job he had pursued—and obtained—all on his own. Wayne was a cheerful, outgoing presence in our household, spent time with his friends (and a girlfriend or two) and had an eye toward an acting career. My son seemed to have everything going for him.

Things changed

It's hard to reconcile that image with the gaunt 18-year-old who now sits, day in and day out, in a darkened living room, motionless, with downcast vacant eyes, no longer capable of, or interested in, any sort of sustained conversation. This is mental illness. This is psychosis.

He is preoccupied with vivid, puzzling and conflicting images and ideas. Thoughts start out clear in his mind, but before they're fully processed, they collide with one another, shattering. Just sitting quietly considering these jumbled thoughts can easily consume most of his time.

The rest of the time, his interests become unhealthy obsessions such as with the underground rap

band Insane Clown Posse. It's the same with his spirituality; he carries a Bible everywhere he goes and rejects or accepts ideas based on his interpretation of God's word. Not in a wholesome manner, but like a zealot. Psychosis colours his life.

Psychosis takes many months to develop to the point of the sufferer having any clear, recognizable symptoms. To a parent it can look like adolescent rebellion or the result of teenage drug use. The illness is hard for him to recognize. After all, it's a disease of the brain and the brain is the organ that must recognize the illness.

But the behaviours are hard to ignore. I tell him that it's not appropriate to lie down and do "exercises" in the middle of a crosswalk on 10th Avenue. I tell him that normal people don't bend and kiss the pavement every 30 seconds. I stop him from kneeling in his pajamas in the mud of our driveway. Wayne understandably resents my constant reminders that he is 'crazy.' But no person in this world cares more for Wayne's well-being than I. My voice is the one that has rattled in his head, begging him to accept treatment, pointing out symptoms that he cannot—will not—see, in a desperate attempt to help him get well.

Untreated, psychosis continues to progress—with frightening potential consequences. Not all people with psychosis become violent, but many, even the most placid and caring of individuals, do. Depression, too, visits periodically. Many people with long-term psychosis eventually commit suicide.

Terrible responsibility

Last year, my son's illness reached a level of severity that allowed him to entertain and then act upon a frightening idea. With a kitchen knife, Wayne attempted to cut off his testicles. Fortunately, the pain and the blood—or some semblance of sanity—caused him to abort the operation before the act was completed, and to seek help.

The wound was closed and healing within a few weeks, but Wayne failed to go for required follow-up care despite concerns about complications. He's chosen to reject this medical treatment—along with the mental health assessments and drug therapy.

On attitudes – The community

When I think back to last summer and how the changes in Wayne's demeanor were reflected in the faces of our adult friends and neighbours, above all else, I recall their concern and kind words.

Wayne spent his days during a heat wave running awkwardly up and down the side of the highway. He could never make up his mind where he was going; he just needed to be on the road. He was 25 or 30 pounds under weight and his clothes were rumpled and smelly; he wore layers of them. His face was unshaven and his eyes like dirty gray rocks from the driveway.

But people—many, complete strangers—just kept pulling up and dropping him off at our home. They'd find him wandering or standing gazing into their neighbours' yards, or maybe sitting motionless for hours in the long grass near the highway, and they'd offer him rides in their cars. "I'm so amazed at the scope of human kindness," I told my husband. "He looks odd and scary. You wouldn't think they'd pick him up." I was surprised to discover how many other families have been touched by mental illness.

"Everyone I talked to just wanted to help in some way," my husband reminded me recently. When he said that, it made my stomach do a little flip-flop.

continued on page 30

Looking Into the Cultural Mirror

Addiction, secret lives and lost personhood

“...I, being poor, have only my dreams; I have spread my dreams beneath your feet;
Tread softly because you tread on my dreams...”

— William Butler Yeats

For months, a woman sat outside a housing agency and repeatedly stabbed herself. “She’s just doing it to get attention,” the staff said. One night, she killed herself. A man living with an active addiction went to a hospital to treat an infection. A clinician told him to go home to his “box in the Downtown Eastside” until he was “clean from drugs” and then he could return to have his infection treated.

Both these stories illustrate the existence of “cultural zones of friction.”¹ Stigma is often found at the centre of these zones, particularly the case for addictions. This article explores the process of stigmatization at the heart of our understandings of addiction and its inevitable outcome: the production of suffering for people who are relegated to the cultural shadows of life.

Why do we fear and loathe addiction so much? Does it speak to our innermost fears as individuals and a society? Does it somehow take away that which we cherish most about our humanness? Do we fear addiction because of the loss of control over our selves it brings? What greater fear exists for us all than to lose such personal control? Perhaps addiction doubles this fear, since addicts appear unable to control themselves—and we cannot control them either.

People influence culture and are likewise influenced by culture. The notion of what it is to be a *person*, as opposed to a piece of sandstone, a rattlesnake or fingernail clipping, is a broad-reaching and important concern in most, if not all, cultures.² A person comprises many parts: life experiences, a past, a family with obligations, work history, a culture, physical characteristics (how we look to ourselves and others), relationships, emotions, consciousness, sexuality, a political side, a body, per-

ceptions about the future, secrets, fantasies, hopes and dreams, as well as roles such as father, mother, brother, sister, anthropologist, teacher or orphaned son.³

Personhood provides information about an individual’s membership in society. Membership in society brings with it a sense of personal value, belonging and inclusion as a part of the human family. Socially compromising attributes such as having an addiction degrade an individual’s personhood to a tarnished, diminished state.⁴ People with diminished value are considered to be “not quite human” and their “life chances” are reduced.⁴

While addiction impacts all social classes, addicts are typically relegated to a lower social position and are often placed at a social distance from others. This results in a kind of social death and is due to a number of distinct social blemishes that impact the personhood of addicts. These social blemishes result in the marginalization of people with addictions and, as a result, create implicit or explicit barriers to health care and social services.

People with addictions combined with other health and social challenges have acquired many labels, including hard to house, hard to reach, multiple barriered or multiply diagnosed. The various labels layered onto this group often perpetuate the demonization of this vulnerable population by implicitly blaming them for failing to conform to various systems: health care services such as hospitals, emergency wards and acute care facilities; pre-trial centres, law enforcement and other criminal justice services; and social housing.

Addicts are aware of threats to their personhood brought by the stigma of addiction. In some situations,



R. Dan Small, PhD

Dan works with the Portland Hotel Society, in Vancouver’s Downtown Eastside

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2. Geertz, C. (1975). From the Native’s point of view: On the nature of anthropological understanding. *American Scientist*, 63, 47-53.
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4. Goffman, E. (1963/1986). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.
5. Giddens, A. (1991/1997). *Modernity and Self-identity: Self and Society in the Late Modern Age*. Stanford, CA: Stanford University Press.
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these threats are so great that people need to employ dramatic strategies in order to survive. For example, Giddens describes the condition of anorexia as reflecting a situation where the person does not feel safe, even in their most personal sanctuary, their body. They therefore reject their own body as a home for their self.⁵ Addiction, like anorexia, can be seen as a strategy for creating control over the story of one's own personhood. For the anorexic, the body is alien, a place where the self does not have a home, while for the addict, society is the place where the addict's self is homeless.

Suffering is a challenge to personhood, and is not restricted to physical pain. Nowhere is this truer than in addiction. Addicts suffer biologically, psychologically and socially. Suffering is a complex personal experience that can come about due to a number of things such as the anguish of a loved one, physical agony, powerlessness, hopelessness, homelessness, memory failure, loss of friends, lack of validation, lack of meaning, isolation, loss of a secret dream, an inability to work, or fear of the destruction of one's self as a person.³

A physician writing on the importance of addressing human suffering in treatment wrote that one of the key elements of personhood is a secret life.³ This secret life may be composed of secret passions, hopes, lovers, ambitions and dreams. Addicts, too, have secret lives. But addiction damages not only people's bodies, but

also their public and secret selves.

Traditional anthropologists were fascinated by 'far-away' cultures, which opened a secret window for anthropologists to compare these 'exotic' cultures to their own. The anthropologists were often disparaging in the way they examined and classified other cultures as less developed and 'civilized' than their own (usually Western) culture. Similarly, the most marginal in our society, drug addicts, are the focus of a kind of public anthropology and voyeuristic fascination. Each year a new demon drug (this year it's crystal methamphetamine) generates public panic and worry about moral decline.

In order to best develop accessible services for people with active addictions, we need to uncover the "cultural scaffolding" surrounding addiction that underlies professional practice.⁶ The soundest and most ethical strategy for removing barriers to access begins with turning the analysis inward to ourselves as professionals, to uncover the values we hold that hinder our approaches to helping marginal populations.

Maybe the most marginal and forgotten people in our community are not really evil 'others,' but are instead a mirror of our own cultural anxieties. If we looked into this cultural mirror, what would we really see? Would we see the personhood of people living with addiction in danger of being further wounded by our disapproving cultural images? ■

Adjusting Our Dreams | cont'd from page 28

**On attitudes –
Closer to home**

One sickening comment will always colour the summer of 2004 for me.

My sister Joanne and her husband brought their beautiful baby girl, Mikaela, to visit. Wayne was entranced; he just watched her. Every time Joanne put Mikaela down to bed in

their travel trailer, Wayne would sneak in to watch her sleep. A couple of times he picked the baby up. Joanne kept asking him not to, but whenever she turned her back, there he'd be.

She and I watched from the kitchen window one afternoon as his lanky shape stepped up to the

trailer door. We watched through the window as Wayne stood there looking down at the crib. I imagined Mikaela's soft blonde curls, fat cheeks, her baby smell. Who wouldn't want to watch her sleep?

"It's just that she needs to sleep and he keeps waking her up," said Joanne. "If she doesn't sleep now..."

"No," I said softly, "It's not just that, is it? We don't

know what he'll do, do we? What made him hurt himself that day? If *that* could seem okay to him, what else might?"

Sickened, I went with my sister to coax Wayne away from the baby.

The comment I uttered in my kitchen that day—*myself!*—was the most hurtful thing anyone has said since psychosis came to visit. ■

Genetic Counselling
and Mental Illness
Helping Families and
Fighting Stigma

Genetic counselling is...

People usually only think of genetic counselling as something that applies to pregnancies where there is a chance the baby could have a condition such as Down syndrome. Genetic counselling is rarely thought about as something that might benefit people dealing with mental illnesses such as schizophrenia or bipolar disorder. But it can be very useful for families affected by major mental illnesses—and can help fight against the stigmatization of mental illness.

Genetic counselling is often regarded warily. This is understandable, because unfortunately, it has an unpleasant past. Its origins are tied to the birth of eugenics (i.e., controlled breeding of human beings), which involved many horrific human rights violations. The forced sterilization of 2,800 people with mental and physical disabilities in Alberta between 1928 and 1970 is just one example.¹

A desire to avoid repeating the mistakes of the past, however, has helped modern genetic counselling develop into a profession governed by “non-directiveness.”² This means that genetic counsellors will not make decisions for their clients, or advise them not to have children because they have a mental illness. Genetic counsellors believe that when their clients have all the information and support they need, they are the best people to make their own decisions.

Genetic counselling is a communication process. It deals with problems that involve an illness where genetics plays a role. Mental illnesses are “complex disorders,” which means that both genes and the environment affect the development of the illness.³

We know that genes play a significant role in schizophrenia, bipolar disorder, schizoaffective disorder and OCD, and a slightly smaller role in alcoholism, panic disorder and major depression.⁴ Genetic counselling for mental illness helps people understand the roles of both genes and environment in how the illness developed, and helps them make the best adjustment they possibly can to the illness in their family.

Women with mental illness who are pregnant or who want to become pregnant, may find genetic counselling useful. The prospective parents may want to know the chances of the baby developing a mental illness, or they may want to talk about how medications might affect a developing baby.

The following individuals may also find genetic counselling for mental illness useful:

- People who have a mental illness and who want to know “why me?”
- Parents of individuals who have a mental illness, who have felt guilty, wondering if they somehow caused the illness, or who were previously told that the illness was “their fault”
- Brothers, sisters or children of individuals with a mental illness, who are afraid they might also develop it, or that they might ‘pass on’ the illness to their children

Each genetic counselling session is unique. Usually, the counsellor starts by helping the client work out what they want to achieve or to learn in the session. This can be very different from person to person. The counsellor will ask the client about their experience of the illness, and what appeared to cause or trigger it. The counsellor will ask about, and draw, the client’s family history. If the client would like to know what the chances might be for other family members to be affected with a mental

illness, the counsellor will try to give this information. Counsellors will also help clients make decisions related to the counselling session by providing information and support, and by connecting clients with support groups. They also provide the opportunity to explore the impacts this new understanding might have.

How can genetic counselling help fight stigma?

Fear of mental illness is one of the most significant factors contributing to stigma, and uncertainty about what causes mental illness is one of the things that makes people afraid.

Helping families to understand the causes of mental illness will not only help to decrease guilt and anxiety, but will also help to demystify mental illness and increase the sense of personal control. We know that many people share their new knowledge of the causes of mental illness with friends and family, which helps to demystify mental illness within the community. Demystifying mental illnesses should decrease fear, and reduce avoidance and discrimination against people with mental illness and their families.⁵

Genetic counselling is usually only offered to families affected by conditions that are caused entirely by genes (e.g., cystic fibrosis or Down syndrome). Or, it is offered to families affected by diseases for which genetic tests are available (such as some kinds of breast and ovarian cancer).

Mental illnesses are not caused entirely by genes and there are no genetic tests for them. As a result, families affected by mental illness are not usually offered genetic counselling.

If, having read this article you are interested in genetic counselling, ask your doctor to make a referral for you at 604-875-2157. ■

Jehannine Austin,
PhD, CCGC

Jehannine holds a doctorate in neuropsychiatric genetics, is a certified genetic counsellor, and a clinical instructor in the UBC Department of Psychiatry. Through the South Fraser Early Psychiatric Intervention program, she works exclusively with families affected by mental illness. Jehannine plans to set up Canada’s first specialist genetic counselling service for mental health concerns

footnotes

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Canadian Anti-Stigma Campaigns

A review

Naomi Liu

Naomi is an undergraduate Communications and Publishing co-op student from Simon Fraser University. She currently works in the Public Education Department of Canadian Mental Health Association, BC Division

The realities of discrimination and social exclusion have prompted the use of public relations campaigns in an attempt to influence people's attitudes and behaviours toward those with a mental illness. Most of these campaigns have used mass media as a singular or secondary avenue of persuasion. I've chosen to highlight a few examples of Canadian campaigns.

Transforming Lives campaign (2005)

A quick look at history—and movies like *A Beautiful Mind* or *Shine*—shows us that brilliance often walks hand in hand with mental health problems. Sigmund Freud for example, is thought to have lived with some of the very mental ailments that he diagnosed his patients with.¹

Celebrities are able to play an important part in influencing the public's opinion on topics relating to mental health. In the last millennia, public figures like Marilyn Monroe, Abraham Lincoln and Alanis Morissette fought to keep their personal battles out of the critical eye of the media for fear they would be wrongly judged and faced with sinking careers. Many others, however, such as Rafe Mair, Elizabeth Manley, Svend Robinson, Lorraine Bracco, Mike Wallace, Brooke Shields and Alex Rodriguez, courageously share their stories of mental illness.

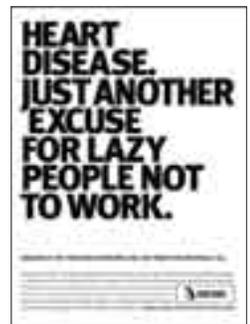
In April of 2005, the Centre for Addiction and Mental Health (CAMH), based in Toronto, launched the Transforming Lives awareness campaign. This two-year campaign features notable public figures such as hockey star Ron Ellis, television host Dan Carter and

former federal finance minister Michael Wilson discussing their personal journeys with mental illness through print, radio and TV public service announcements (PSAs). The CAMH campaign follows in the successful

footsteps of the landmark New Zealand campaign, Like Minds, Like Mine, which has used a similar long-run, celebrity-spokesperson approach. (For more about the Like Minds campaign, see the article by Mykle Ludvigsen on Marketing to Men, an exclusive online *Visions* article available at www.heretohelp.bc.ca/articles).

"Imagine..." campaign (2004)

In 2004, the Canadian Psychiatric Research Foundation (CPRF) also launched an advertising campaign using print, radio and television spots in hopes of addressing the public's misconception of mental illness. The ads asked people to juxtapose how they treat people with physical conditions or disabilities with their treatment of people with psychiatric disabilities.



select screen shots from the CPRF TV ad (below) and sample poster (right)



"Imagine if we treated everyone like we treat the mentally ill," was the tagline accompanying each message. A man hit by a car while crossing the street lies motionless on the pavement. "He's not bleeding, he probably just doesn't want to go to work," a woman proclaims, mimicking the comments many employees overhear from co-workers when returning to work after a mental health crisis.

These public service announcements won numerous awards and received worldwide recognition, including a United Nations Department of Public Information award for producing a message that best reflected the values and concerns of the United Nations. The campaign archives, including multimedia files, can be found online at www.cprf.org.

CAMH posters featuring celebrities like hockey player, Ron Ellis (above), and Ontario TV personality, Dan Carter (below)



BC Association of Broadcasters' Humanity Award campaigns (2003–2004 and 1998–1999)

Every year the BC Association of Broadcasters awards more than \$3 million in donated air time to a social marketing cause. In the past several years, two mental illness-themed campaigns—each with provocative and hard-hitting messages—were honoured with the Humanity Award.

One of the award-winning campaigns was presented by the Canadian Mental Health Association's BC Division in 1998–1999. It featured three bus shelter posters showing a person's face and life activities, with a diagnosis overprinted on the face and the caption, "Don't let your attitude be their disability." The campaign also featured a series of radio ads with the tagline, "To some I'm a problem. To others, I'm a person. How do you treat mental illness?" There were two TV spots—the most famous one, known as the father-and-baby ad, depicted a man cuddling his infant child, followed by the message "This man has a mental illness....But what's really sick...is how your attitude of him just changed."

The more recent campaign has targeted stigma in a similarly provocative way in terms of schizophrenia. The BC Schizophrenia Society's We'd Like to Change Your Mind campaign featured a well-aired TV spot of a young man disclosing his schizophrenia diagnosis to friends in a diner. Written captions beneath the dialogue describe the highly negative fears and thoughts of the friends, in radical contrast to their outward 'supportive' response to their friend's disclosure. The campaign paints a face of schizophrenia that counters stereotypes and points out that prejudice is increasingly subtle and driven underground.



two of the three posters from the CMHA BC campaign

How effective are these campaigns?

Research suggests that campaign efforts aimed at reducing discrimination towards those suffering from a mental illness fall short of producing a measurable impact.² But this isn't unique to mental illness campaigns; the vast majority of *social marketing* efforts—that is, marketing efforts aimed at advancing a social message or affecting attitudes and behaviours—are usually only able to register, if measurement is done at all, a slight increase in awareness levels.

We live in a society that tends to disregard advertising the first few times it is viewed. To be effective, ad campaigns aimed at changing the mindset of the public must be sustained, and combined with multiple approaches. Advocacy at a systems level, to draw attention to policies and procedures in society that discriminate against people with mental illness, is one approach. Grassroots interaction, to bring people with personal experience of mental illness in direct and meaningful contact with those most likely to change their attitudes, is another approach.

We also need to consider how we're evaluating 'success' and measuring changes in prejudice levels.² Do we survey potential members of the discriminating

public to test their attitude shifts (and can a research tool honestly tease out politically-incorrect attitudes?), or do we poll people who have been stigmatized in the past to gauge their sense of changes in community responses over time? Or do we look at behaviours themselves? All of these are difficult questions.

There are critics who suggest that money and energy are better spent on recovery and treatment options for people with mental disorders, as they are the most likely avenue to effect change.

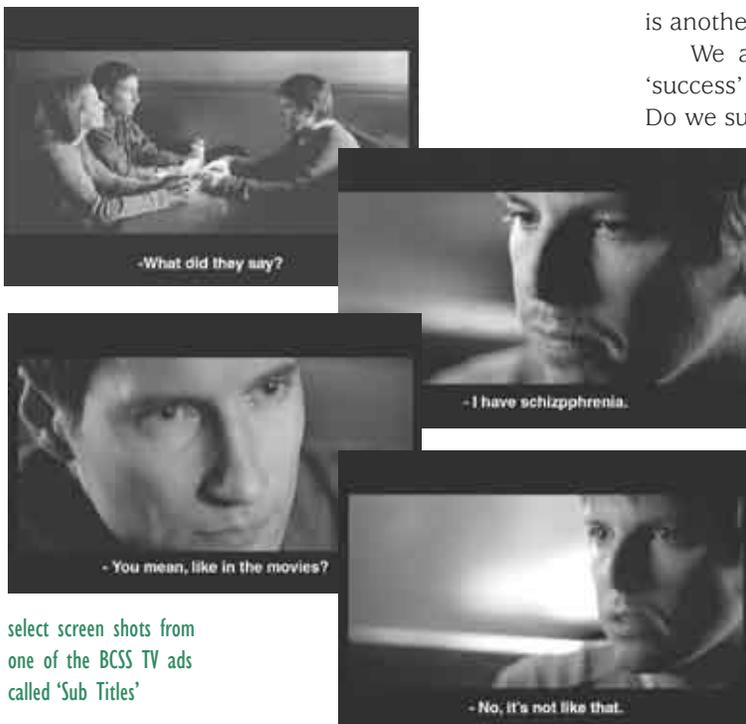
Although there is a definite increase in awareness surrounding mental illnesses, we still have a long way to go in terms of social acceptance. Mass media messages may be one tool in the arsenal, but are by no means a magic bullet. ■

related resource

to learn more about US campaigns in this area, go to www.nami.org and in the search box, type "national efforts." Three PowerPoint presentations on US anti-stigma programs, from NAMI's 2005 convention, should top the result list.

footnotes

1. Buchwald, A. (1999). Celebrity meltdown: Famous, important people who have suffered depression. *Psychology Today*, 31(6), 46.
2. Stuart, H & Arboleda-Flórez, J. (2001). Community attitudes toward people with schizophrenia. *Canadian Journal of Psychiatry*, 46, 245-252.



select screen shots from one of the BCSS TV ads called 'Sub Titles'

Bad Endings

Bruce Saunders

We sat there riveted, watching the SWAT team taking positions. A 'manic-depressive' had taken a hostage, had taped a sawed-off shotgun to a terrified woman's arm, aimed at her head. The SWAT sharpshooter finally dispatched his target. We breathed a sigh of relief. At the same moment I was struck with the irony that we were all sitting there in our gowns after snacks in the Eric Martin Pavilion (Victoria's psychiatric hospital). It was a pivotal moment that led me to start my film series in the auditorium downstairs, in the same building. I always look to that as an example of poor programming. It inspired me to do better than that in my series.

Bruce is the force behind Movie Monday and the Reel Madness Film Festival in Victoria. His bipolar condition has twice hospitalized him in the Eric Martin Pavilion at Royal Jubilee Hospital, which houses the 100-seat Movie Monday theatre. Bruce is also a landscape maintenance gardener

For more information on Bruce and Movie Monday, see islandnet.com/mm

Lately I've become very conscious of bleak endings in movies about people with mental illness. It's true that too often we do have nasty endings. But in films that are fiction, stories can be told without the quick and tidy jump off the bridge or rooftop, the hanging, and the overdose as convenient plot devices. They happen often enough in real life. I was nearly one of those suicide fatalities. But having survived, and finding my life turned around as I never imagined it could when I was suicidal, I now seek out positive models of success to support my recovery.

I can see the power of movies in our society. They are persuasive, and it's important to realize what we are being taught. When screenwriters don't choose more positive endings for their protagonists, we, as people with disorders that come with a fair dollop of hopelessness, are encouraged to accept suicide as an appropriate end. We've got to be careful about what templates we put out there for people balancing on the edge.

For 12 years now I've been showing films in my weekly Movie Monday series in Victoria's psy-

chiatric hospital, using the opportunity to explore film depictions of mental illness and recovery.

Movie Monday screenings like *Ordinary People* and *Dead Poets Society* deal with suicide, as did *Rollercoaster*, *Taste of Cherry*, *About a Boy*, *Mr. Jones*, and even *The Full Monty*. In fact, most films that approach mental illness realistically demonstrate that suicide is an often-present threat.

But the implications of how movies handle the topic of suicide struck me when filmmaker and psychiatrist Dr. David Dawson recently gave us a look at his new feature, *Drummer Boy*, a story of a young man becoming ill with schizophrenia. The protagonist is on the run, paranoid, confused, and unable to cope with the torment. It's an engrossing journey, but Dr. Dawson sends him off the top of a building in the last frames, falling backward to his death. Damn!

I was incensed that this film revealed itself to be yet another in the genre that I have dubbed "schizophrenia snuff films." An earlier film by Dr. Dawson, *Manic*, has a similar outcome. *Can You Hear Me Thinking?*, a film made by

Christopher Morahan for British television, stars Judy Dench and her husband as the parents of a young man who fills his pockets with stones (Virginia Woolf-style) and walks into a lake. Another bummer. We don't need that!

A recent release, *See Grace Fly*, sounded promising. Not! The filmmakers tried to craft an ambivalent ending, but it seemed pretty clear to me: another 'jumper.' *Revolution #9*, a choice in UBC's Frames of Mind series, was equally dismal "leading to tragic results" as the program read. Oh, no! Here we go again... People around us—doctors, kids, parents, neighbours, co-workers, friends—don't need to learn from popular entertainment that suicide is our inevitable outcome.

In contrast, in the film *Girl Interrupted*, a secondary character dies by suicide, but the protagonist survives, writing her story from middle age.

"True" stories about brilliant people who have mental illness, such as *Shine*, and *A Beautiful Mind*, are somewhat embellished, but they are break-out films that inspire many to look at mental illness in a different way.

An Angel at My Table, Janet Frame's biography, is a more realistic film, ending with the subject living a humble writer's lifestyle after a harrowing early life of madness coupled with some positive adventures. We're impressed with her resilience.

During the discussion with Dr. Dawson following his film, *My Name Is Walter James Cross*, I raised something I've learned from various schizophrenia presentations: people with the illness as young adults often tend to experience significant recovery as (and if) they reach middle age. He hadn't heard that.

Dr. Dawson argues that we must realize how dangerous these illnesses are. But I say, please, don't do it by knocking off the person we've spent the last hour getting to care for.

I'll continue to screen films like *The Hours* and even Dr. Dawson's *Manic*. But we'll incorporate discussions. It's a challenge for people with mental illness to build a hopeful outlook into their treatment plan, and in the context of our presentations we can balance the 'inevitable' spectre of suicide in film with some hopeful alternatives. ■

related resource

for more information on Vancouver's Frames of Mind Series, see www.psychiatry.ubc.ca/cme/film or call (604) 822-7610

Mental Illness in Film: A Director's Take

response to bruce saunders

Hi Bruce,

Your thoughtful comments have not alienated me. We actually filmed an alternate ending for the film *Drummer Boy*: the cop grabs the protagonist and the rest is left to the imagination. This alternate ending is sitting in the vault waiting to see audience reactions. A veteran actor who reviewed the script for me used a phrase similar to yours: "You can't have your audience live and breathe and like this kid for two hours and then kill him off." But as John Travolta's character in *Get Shorty* says: "Endings are hard." I have wrestled with these considerations and agree with your comments. The other side of my head, however, uses another argument.

Most American film today is an act of denial. We don't have to worry about the sorry state of the public school system because Meryl Streep will show up and teach all the kids violin. Or another prototypical American hero (free, independent, iconoclastic) will take charge of the high school. Or save us from aliens. Or corruption. Or win the Vietnam War single-handedly. We don't have to worry about 50 million uninsured Americans because a true 'American Hero' can always get a heart transplant for his kid if he shows a little initiative. Now, I enjoy being manipulated as much as anybody. But I think we are doing ourselves an ultimate disservice here.

Shine—the 1996 dramatization of the life of David Helfgott, a renowned pianist with schizophrenia, starring Geoffrey Rush in an Oscar-winning performance—is a wonderfully crafted and acted movie. I enjoyed it immensely. It was only on later reflection that some doubts crept into my mind. Here they are: The word *schizophrenia* is not used. (This harkens back to the days when the word *cancer* would not be used.) The young pianist is driven 'crazy' by the passion of playing Rachmaninoff's Third Piano Concerto—implying a last-century idea that lunacy is the product of a creative, sensitive mind in touch with God. In the film, Helfgott's father didn't want to let his son go to England to study music. The father is portrayed as brutal and controlling. (An alternate explanation could be that his father was a reasonable man, and sensed that his son was not well or strong enough to go travelling on his own. Subsequent events suggest that the father was correct). Then, as portrayed in the film, after years of wallowing in equally brutal mental hospitals, Helfgott finds a piano again, and a woman to take care of him, and lives happily ever after. If we'd only just understood his needs and his passion in the first place!

Here is the probable truth: Helfgott is a very good student pianist. He develops schizophrenia while far from

home. He is hospitalized. His illness is severe and his recovery is minimal. So for years he resides in an Australian mental hospital, which is actually very picturesque with semi-tropical grounds and is located by a beautiful river. (All Australian mental hospitals are found on rivers, by the way. They also all have pianos available for those who can play.) Times change. Now on some medication that improves his illness somewhat, Helfgott is 'integrated into the community.' A woman takes Helfgott on as a project and falls in love with him and marries him, providing a rare protective family environment that allows him to live and thrive. She also controls and monitors his medication regimen. Then, we come along and exploit him.

I think, with both *A Beautiful Mind* (about the life of famed mathematician John Nash, who has schizophrenia) and *Shine*, we are told Hollywood stories that subliminally suggest to the audience that it's okay to be a weird-looking schizophrenic if you also happen to be a genius. And don't you worry about them—if they have any kind of talent or willpower or initiative, they will pull themselves up on their own. This again is a form of societal denial. We are left entertained, even enthralled, admiring, but certainly not worried, not guilty, not feeling responsible or challenged in any way.

We, as viewers, don't like the ending of *Drummer Boy*. But that's the point. Maybe if we worked or tried a little harder, understood or paid attention a little more to the mentally ill, the ending would be different for the protagonist.

I don't know which is right. As pure drama, the death of the protagonist (although it is not a high building and we simply see him floating away and some viewers have chosen to see this not as a death) is classic tragedy. As an affecting experience for the audience I think the death brings tears, causes the story to linger in the mind, and may influence perception and ultimately action. Whenever *Drummer Boy* has been shown, someone has come up to me with tears in their eyes, and talked about a brother or sister—often a brother or sister who is living in an institution or supportive housing and kept out of mind as much as possible. Viewers also tell me that after seeing the film they understand more about mental illness in general and schizophrenia in particular. A different ending would show rescue, hope and new possibilities. Would it be as effective? The words of Willy Loman's wife in *Death of a Salesman* are the ones that should ring in our ears: "Attention must be paid."

*All the best,
David*

David Dawson,
MD, FRCP

Dr. Dawson is a semi-retired psychiatrist and educator, and a past Chief of Psychiatry at Hamilton Psychiatric Hospital. He is an artist, owner of Gallery on the Bay in Hamilton, Ontario, a published novelist, and a filmmaker, who uses film to explore realistic portrayals of mental illness

Partnership Education Program

Increasing awareness, decreasing stigma and discrimination

Nicole Chovil

Nicole Chovil is Director of Education with the British Columbia Schizophrenia Society

For further information about the Partnership Education program, contact your nearest BCSS regional coordinator or branch, or visit the BCSS website at www.bcscs.org

Education about mental illness is critical to enhancing the lives of people with mental illness and their families. They often indicate that stigma is harder to deal with than the disease itself. Uninformed attitudes compound the difficulties experienced by those with the illness and by their families who support them. Mental illness education humanizes and demystifies the disorders. Understanding leads to compassion and acceptance.

The Partnership Education program is offered through the BC Schizophrenia Society (BCSS). It uses personal storytelling as a basis for informing people about mental illness. A person with a mental illness, a family member and a mental health professional, brought together

in a climate of trust and respect, share their experiences to educate community groups about serious mental illness. These team members each talk about mental illness from their own perspective. This provides audience members with an opportunity to see the ‘whole picture’—not just one perspective.

The two main goals of Partnership presentations are 1) to present information and facts about schizophrenia and other serious mental illness in order to increase awareness and understanding in communities, and 2) to achieve closer relationships between consumers, family members and professionals.

The model we use has proven to be a powerful technique for educating the community about mental illness. Since 1990

the Partnership program has been used in communities throughout BC, and the demand for presentations is ever increasing.

Objectives

The program is an education vehicle designed to:

- Dispel myths about mental illness
- Inform the public and other agencies of the facts about schizophrenia and other serious mental illness
- Humanize mental illness issues by focusing on the people rather than the diagnosis
- Reduce stigma and discrimination
- Help build relationships between professionals, families and consumers
- Maintain ongoing communication about the needs of families and consumers
- Empower families and consumers by providing training in skills necessary to work with others and to speak out
- Improve the chances of timely intervention and treatment by increasing public awareness and recognition of mental illness symptoms
- Reduce the negative impact of mental illness on the community

Benefits for team members

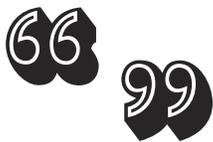
Participants receive many

benefits including the opportunity to work as part of a team which can also enable panel members to learn of other perspectives on mental illness. Panel members also report increased self-esteem, pride and enjoyment in knowing that one is providing a valuable service. Skills training for each team members allows them to practice areas in communication and presentation that are needed to effectively present their stories. This, combined with planning, evaluating and debriefing, allows for feedback to make improvements.

One psychiatrist remarked about a client panel member: *“She’s developed significant confidence through the opportunity to do public presentations from a patient’s perspective. She feels much more adept socially... and this all gave her a much more solid sense of herself and from that evolved a new relationship with her illness.”*

Results

- Increased confidence and improved skills of presenters
- An appreciation for the presenters by the audience members
- Increased public awareness of the prevalence of mental illness (i.e., it can happen to anyone)



sample audience responses

- “We need reminding that this matter of mental illness is complex and we should not stereotype it.”
- “True stories from real people. This is an excellent presentation, very informative and worthwhile. Everyone’s personal experiences helped me to understand how it actually affects people.”
- “Excellent presentation! We admire your courage.”
- “The presentation personalized the issue and the information I have learned will assist me in dealing with the mentally ill in my job and in everyday life.”
- “It was truly wonderful to learn about a subject that is usually kept on the back page of the paper.”

- Better service quality for consumers and families
- Better understanding and increased knowledge of mental illness and its effects on individuals and their families and friends
- Increased ability of people with mental illness and their families to cope, adapt and initiate changes within the mental health system
- Increased support and improved communication amongst people with mental illness, family members and mental health professionals

Who can request a Partnership presentation?

Everyone can benefit from education about mental illness. Partnership presentations have been made to church groups, public transit drivers, police departments, hospitals, mental health centres, home support workers, financial aid workers, crisis lines, lay counselling services, social workers, high schools, colleges, universities, medical and professional associations, counselling centres, senior centres, and service clubs. ■

Opening Minds

Open Minds Open Windows (OMOW) is a mental health services charity formed in Nanaimo in 2002. Its mission is to reduce the stigma and prejudice surrounding people with mental health issues. Its goal is to target two areas of stigma: the stigma that a person with a mental health issue holds and the stigma society holds.

I created the Open Minds Open Windows concept of how to reduce stigma while I was providing care for my son as he struggled with a mental health issue. I was already involved with one mental health organization. Then I developed a mental illness, which took me into a psychotic manic state, and my ideas about how to fight against stigma became quite grandiose. When I came out of psychosis, I gathered together 11 hand-picked people, not all known by me. This group talked me into reducing my grandiose ideas, and then began creating 'grandiose' ideas of their own, which magically began to conform to my ideas and even expanded on some.

Mental illness touches almost every family in some manner, and not one of the 11 people I approached hesitated to become involved. They consist of two retired businessmen, four active business people, two people with knowledge of mental health issues, two musicians, and a still life artist. The 12 of us became the keystones of the organization, and as directors we all have hands-on involvement in each of the OMOW projects.

Our idea was to use the arts and humanities as an avenue of approach to deal with stigma. What has been accomplished to date is the production of two annual concerts in Nanaimo's 800-seat theatre. Both received standing ovations from full houses.

The first concert, in 2004, presented six mental health stories, using local professional actors to act out scenes while local professional dancers also interpreted the stories. The stories were interspersed among performances by professional musicians, which were interpreted on canvas by a visual artist.

The concert in 2005 replaced dramatizations with poetry readings, and closed with a two-song finale per-

formed by Beautiful Minds, a choir comprising 18 people with mental health issues. The choir was conducted by a musician who had been so moved by the 2004 concert that he volunteered to form this choir. Beautiful Minds has since been invited to take part in an annual fair held in Nanaimo's south end and has two other gigs lined up as well.

Open Minds Open Windows also uses approaches other than the arts to fight stigma. The organization showcases people with mental health issues at a variety of community events. The Nanaimo mental health centre's Day Program participants painted rocks and sold them during Nanaimo's Bathtub Race festival. We entered a float in the local Empire Day parade and won first prize in its category. We've played ball with the local RCMP and taken on local Junior 'B' BC hockey champions. People with mental health issues have taken part in two psychology forums organized by OMOW at the local campus. And, a 17-song CD was created with 16 professional musicians who donated their songs; Day Program participants wrote and recorded the 17th song.

New initiatives include a special project with a local, renowned First Nations carver who is teaching not only his carving skills, but also his holistic view of life, to four people with mental health issues. A contract with GO Rowing and Paddling Association of Canada has begun, with two one-and-a-half-hour paddling sessions held each week for the next four months. Each canoe, capable of holding 24 people, will provide exercise and socialization for those who do not wish to compete. For those who enjoy competition, a team will be created to take part in the Dragon Boat Festival in Nanaimo from July 8 to 10. Other projects are in the works.

While there is much still to do, OMOW has made significant strides in its short three-year history. We recognize that there are many people in our society who are willing to assist with projects, and as each event is held, more opportunities present themselves and more people in the community respond. ■

Ron Plecas

Ron is Chair of the Nanaimo Mental Health and Addictions Advisory Committee, Director of the Nanaimo branch of BC Schizophrenia Society, and the founder and Co-Chair of Open Minds Open Windows. Ron is diagnosed as bipolar

Changing Attitudes at VIHA

“A significant challenge in developing welcoming, effective services is the stigma that exists concerning addictions. Strong moral stances are prevalent among service providers and in the community. This orientation training was fantastic in addressing my own values and beliefs and helped me to begin thinking about how I can change my own practice and perhaps influence the practice of my team.” — MHAS Professional Development Day participant

Michael Reece, RN, and
Sara Bristow, MEd

Michael is Clinical Nurse Educator with the Vancouver Island Health Authority. He has worked in the mental health and addictions field for several years, with experience in emergency room psychiatric care and inpatient care

Sara is a Comprehensive, Continuous, Integrated System of Care (CCISC) trainer. A clinician and leader in the addictions field for 15 years, she works with VIHA and the community, providing addiction prevention services, consultation, education and resources

The subject of mental illness and/or substance abuse can generate considerable misunderstanding, prejudice, confusion and fear. Individuals known to have mental illness and/or addiction may find it more difficult to find employment, be approved for a loan, or rent an apartment, even if they are well at the time.

To make matters worse, health care providers can sometimes poorly serve those with a mental illness and/or substance addiction. Practitioners may be less willing to offer support and empathy if someone is suffering from a mental illness rather than a physical health problem. Due to their complex presentation, those experiencing mental illness and/or substance addiction tend to over-utilize scarce health care resources, and they rarely fit into traditional medical treatment modalities. Individuals diagnosed with mental health or addiction concerns are often thought to have ‘done it to themselves’ and do not usually respond to ‘quick fix’ remedies. Inevitably, this population produces difficult-to-predict clinical outcomes and creates higher treatment costs for an already stretched health system.

Dr. Ken Minkoff, a psychiatrist and advocate, describes this population as “system misfits.”¹ Why? Because he has identified the social prejudices within health care settings against this already marginalized group, and has a comprehensive understanding of how old mental health and addiction health care philosophies have failed to meet the needs of this clientele.

To help address these issues within the Vancouver Island Health Authority (VIHA), Mental Health and Addictions Services (MHAS) has announced its commitment to welcoming people who present with both mental health and/or substance use concerns. MHAS is committed to improving treatment outcomes by creating *empathetic* and *welcoming* relationships within programs, and providing appropriate services matched to the needs of the individual, their stage of change and phase of treatment. MHAS recognizes that meeting the needs of people with mental health and substance use issues requires an effective, integrated and coordinated continuum of services that, collectively, will address a wide variety of consumer concerns.

To further support this initiative, MHAS is providing its service providers with professional development edu-

cation on current mental health and addiction topics.

As part of MHAS’s Comprehensive, Continuous, Integrated, System of Care (CCISC)² initiative, a cadre of trainers is developing a series of educational workshops focused on core competencies for understanding mental health and addiction. One professional development workshop has already been developed in partnership with the South Island MHAS Practice Resource Team. This free training is offered one full day per month and is available for new MHAS employees, affiliated college and university students, and other health professionals wishing to build upon their skills and knowledge within the field of mental health and addiction.

The morning session, facilitated by a CCISC trainer, focuses on theoretical models of addiction, beliefs about addictions and mental health, stages of addiction, life areas affected by concurrent disorders, harm reduction, stage model of change, and principles of motivational interviewing. The afternoon session, facilitated by the Practice Resource Team, focuses on comprehensive mental health and addiction assessment strategies, psychiatric emergencies, suicide and aggression. It includes abbreviated sessions on psychotic disorders, personality disorders, mood disorders, anxiety disorders, eating disorders, and the Mental Health Act. In addition, a plethora of teaching material is handed out to the participants. One of the most prominent resources distributed is the BC Partners for Mental Health and Addictions Information *Primer*.³

Since January 2005, over 100 service providers have attended the Orientation to Mental Health and Addictions training. Evaluations from participants and program coordinators are extremely positive with outcomes including increased awareness of personal biases, of the importance of the stages of change when supporting people, and of harm reduction strategies.

This new educational initiative of VIHA’s Mental Health and Addictions Service intrinsically encourages improved treatment outcomes by creating empathetic and welcoming relationships, and by providing appropriate services matched to the needs of each individual, their stage of change and phase of treatment. We hope this article has led you to reflect on your own beliefs concerning social prejudice within our field. ■

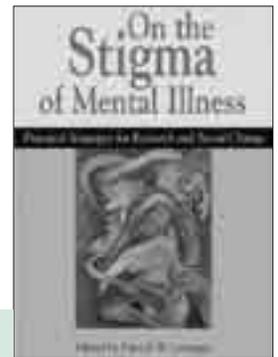
footnotes

1. Minkoff, K. (2001). *Dual Diagnosis: An integrated model*. (Presentation).
2. Mindoff, K. (2004). The Comprehensive, Continuous, Integrated System of Care model. *Visions: BC’s Mental Health and Addictions Journal*, (2)1, 45-46.
3. BC Partners for Mental Health and Addiction Information. (2003). *The Primer: Fact sheets on mental health and addictions issues*. See www.heretohelp.bc.ca/publications/factsheets

On the Stigma of Mental Illness

Practical Strategies for Research and Social Change

Edited by Patrick W. Corrigan. Washington: American Psychological Association, 2005. 343 pp. Review by Mailis Valenius



According to the book, *public stigma* is “the result of a naïve public endorsing the stereotypes of mental illness” (p. 12). Labels and stereotypes lead to prejudice and discrimination, which can affect a person’s opportunities, such as obtaining competitive employment and living independently in a safe, decent home. The impact of stigma also affects family members, friends and mental health service providers. *Self-stigma* is defined as “the consequences of people with mental illness applying stigma to themselves” (p. 12). By internalizing the stigma endorsed by the ‘public,’ people with mental illness believe they are less valued because of their psychiatric disorder. Self-stigma may result in lowered self-esteem and a lack of confidence which, again, can significantly interfere with life goals and quality of life.

The book does point out that stigma’s effects are not uniform. Many people with mental illness, for example, are aware of the negative stereotypes, but do not buy into them. Not everyone with a mental illness experiences low self-esteem. Some individuals become energized by prejudice, expressing “righteous anger” (p. 26). Others are indifferent and

ignore the effects of public stigma altogether.

Stigmas are also not the same across disorder groups. For example, Chapter 10 outlines how substance use disorders are even more stigmatized than mental illness, due to the public’s blaming of people with addictions and perceptions of a lack of self-control, as well as associations with crime and violence. The authors note that changes are needed at the public policy level emphasizing treatment and de-emphasizing punishment.

The “practical strategies” promised in the book’s title include personal empowerment, public disclosure, protest, education, contact, and the role of media and marketing.

In Chapter 11, Corrigan and Calabrese discuss overcoming self-stigma by increasing self-empowerment. People with a strong sense of personal power can have high self-esteem and the confidence to be active decision-makers in their own care. Empowerment may be considered one of the best ways to deal with the adverse effects of self-stigma and psychiatric labels. It can be fostered by giving mental health consumers greater control over their treatment and their reintegration into the community. This also pro-

vides inspiring stories of recovery to counter some prevailing stereotypes.

In another chapter, the authors talk about disclosure of one’s psychiatric history to others as being a powerful tool for change. Parallel lessons are drawn from disclosure of sexual orientation which can be a normalizing, liberating strategy. Of course, public disclosure of mental illness is a decision left to the individual, who must weigh the costs and benefits.

In Chapter 13, protest, education and contact are presented as processes for changing public stigma. Protest strategies are directed against specific stigmas, using a moral appeal to stop behaviours and influences. Education attempts to challenge and replace inaccurate stereotypes with more factual information. Contact involves interpersonal contact between the public and members of the stigmatized group.

The book states that protest may have limited impact on changing overall public attitudes, but can change some behaviours significantly. For example, organized protest may be useful to stop media outlets from running stigmatizing programs, advertisements and articles.

The benefits of edu-

cation may be limited, as evidence from education studies that target racial and other minority group stereotypes is mixed, according to the book. Short-term improvements may be seen; further research is needed, however, to determine the long-term effects of such interventions.

The book holds the greatest hope for the contact strategy to change mental illness stigma. Studies show that contact with a person with mental illness improves attitudes better than either protest or education interventions.

I strongly recommend this book as an up-to-date primer into a very complex field. The book’s contributors maintain a wide view of the subject and its relevance to systems outside of the traditional mental health field, such as criminal justice and addictions. The book would be of interest to academics, consumers, family members, mental health and addictions professionals, as well as law enforcement or criminal justice personnel, human rights and disability advocates, members of the legal profession—and educated lay readers. It’s academic in its approach and therefore most accessible to those with a college education—or who have interest and appetite enough. ■

Review writer:
Mailis is a freelance researcher and writer. She just completed a work practicum at CMHA from Gastown Vocational Services in Vancouver

Book editor:
Patrick Corrigan, associate professor of psychiatry at the University of Chicago and director of its Center for Psychiatric Rehabilitation, is an acknowledged leading expert in stigma and mental illness. Corrigan worked on this anthology with contributors from the Chicago Consortium for Stigma Research, a multidisciplinary team of experts from psychology, psychiatry, social work, law, sociology, and human development

Organizations, Groups, Campaigns

- **Chicago Consortium for Stigma Research.** www.stigmaresearch.org
- **The Resource Center to Address Discrimination and Stigma.** www.adscenter.org
- **Stigmabuster alerts.** National Alliance for the Mentally Ill, US. www.nami.org/Template.cfm?Section=Fight_Stigma
- **SANE stigma watch,** Australia. www.sane.org
- **Like Minds, Like Mine** anti-stigma/media campaign, New Zealand. www.likeminds.govt.nz
- **Stamp out Stigma project,** California. www.stampoutstigma.org
- **Anti-Stigma Project** from On our Own of Maryland. www.onourownmd.org
- **Open the Doors project,** World Psychiatric Association. www.openthedoors.com
- **Center for Psychiatric Rehabilitation.** (2005). **Stigma Survey.** Open to anyone in recovery from mental illness who has encountered stigma and discrimination. www.bu.edu/cpr/stigmasurvey
- **Stigma of Addiction Project.** Centre for Addiction and Mental Health, Canada. sano.camh.net/stigma.htm

this list is not comprehensive and does not imply endorsement of resources

don't forget all the resources listed at the end of Visions articles as well

Books, Reports, Articles

Mental Disorders

- BC Minister's Advisory Council on Mental Health. (2002). **Changing Attitudes, Opening Minds: Discrimination Against People with Mental Illness and Their Families.** www.healthservices.gov.bc.ca/mhd/advisory/publications.html
- Corrigan, P. & Lundin, R. (Eds). (2001). **Don't Call me Nuts: Coping with the Stigma of Mental Illness.** Recovery Press.
- Wahl, O. (1999). **Telling is Risky Business: The Experience of Mental Illness Stigma.** Rutgers UP.
- Angermeyer, M.C. & Matschinger, H. (2005). **Labeling—stereotype—discrimination: An investigation of the stigma process.** *Social Psychiatry and Psychiatric Epidemiology*, 40(5), 391-395.
- Corrigan, P. (Ed). (2004). **On the Stigma of Mental Illness: Practical Strategies for Research and Social Change.** American Psychological Association.
- Sartorius, N. & Schulze, H. (2005). **Reducing the Stigma of Mental Illness.** Cambridge UP.
- **Stigma issue.** (2003). *Canadian Journal of Psychiatry*. 48(10). www.cpa-apc.org
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dice and Discrimination Against People with Mental Illness. Available in book form, CD-Rom and online expanded HTML version. www.stigma.org

- Sayce, L. (1999). **From psychiatric patient to citizen: Overcoming discrimination and social exclusion.** St. Martin's Press.
- World Health Organization. (2005). **WHO Resource Book on Mental Health, Human Rights and Legislation: Stop Exclusion, Dare to Care.** www.who.int/mental_health/policy/resource_book_MHLeg.pdf

Addictions and Concurrent Disorders

- **The Stigma of Substance Use and Attitudes of Professionals (2001) and Stigma of Substance Use: A Review of the Literature.** (1999). Two reports by the Centre for Addiction and Mental Health. At www.camh.net/education/ed_projectsresources_intermed.html
- Meza, E.D., Cunningham, J.A., el-Guebaly, N. et al. (2001). **Alcoholism: Beliefs and attitudes among Canadian alcoholism treatment practitioners.** *Canadian Journal of Psychiatry*, 46, 167-172.
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- Cape, G.S. (2003). **Addiction, stigma and movies.** *Acta Psychiatrica Scandinavica*, 107(3), 163-169.
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- Cunningham, J.A., Sobell, L.C. & Chow, V.M. (1993). **What's in a label? The effects of substance types and labels on treatment considerations and stigma.** *Journal of Studies on Alcohol*, 54(6), 693-699.
- BC Partners for Mental Health and Addictions Information. (2003). **Stigma and Discrimination Around Mental Disorders and Addictions [fact sheet].** www.heretohelp.bc.ca/publications/factsheets