THE RECOVERY OF HOPE ~ THE HOPE OF RECOVERY

LIGHTS, CAMERA ... CAREGIVERS

They may not have Hollywood's glitz, but Stephen Snow's ethnodrama productions offer something more important: a fast track to understanding and the power to heal

If you attended this year's annual general meeting, you saw a fascinating presentation by Stephen Snow, professor of drama therapy and chair of Concordia University's department of creative arts therapies.

Play, therapy and fun, too

He has originated a unique approach to therapeutic theatre he calls ethnodramatherapy, EDT for short. His method uses performance rather than a written narrative to construct an intimate portrait of the participants, their lives, their problems, their joys and fears. Done well, it can be a powerful catalyst for change.

How it's done

The participants are filmed as they tell their own stories in their own words. Then a script is written based on that data and developed into a play, an ethnodrama, which Snow describes as "the mirror of lived experience." The actors can vary from professionals to amateurs, student actors

and members of the original group. The play is performed for interested parties and may later be developed into a film.

You could call EDT a health-education research method, because its ultimate goal is to improve attitudes and even systems.

Snow mentions two projects where change took hold amazingly quickly.

"We had very positive results with the ethnodrama we did concerning people with developmental disabilities. They're one of the most highly stigmatized populations in the world and we wanted to attack that prejudice. Our first idea was to have a performance just for professionals. But then we noticed the play was having a dramatic effect on preteens. We gave them a questionnaire pre- and post-viewing and saw

that their ideas about those who live with a developmental disability were already starting to shift."

Three years ago Snow undertook a yearlong EDT project with girls at Batshaw Youth and Family Centres. "We wanted to see if there would be a change in the audience's perception of the girls and if the girls' self-image would also change. Both happened. Family members said they were just amazed watching their kids saying things they had no idea were felt so deeply and emotionally. There was also discussion about what needs to be improved within the youth protection system." Provoking

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Have you started a Disability Savings Plan yet?

o? Regretfully, you're not alone. Figures show that only 15 percent of eligible Canadians have taken advantage of this good idea that allows parents to begin building a nest egg now for their ill child's future needs.

In effect since 2008, the Registered Disability Savings Plan (RDSP) works much like the vastly more popular Registered Retirement Savings Plan, but with a few significant differences. Only people who qualify for a disability tax credit are entitled to receive the funds deposited in the plan. Contributors, including parents, spouses, relatives or other caregivers, are allowed annual deposits until the beneficiary turns 60. There's a lifetime contribution limit of \$200,000 for private contributors and a 10-year withdrawal wait is required. Unlike the Retirement Savings Plan, RDSP contributions are not tax-deductible.

The RDSP is a generous plan. According to a Senate banking committee report released last March, the government has committed more than \$800 million in grants and bonds to the program over the past seven years. Why then is it so underutilized?

The report states that many Canadians haven't applied because they either don't know it exists (the committee points a finger at a poor job of advertising) or because of unnecessarily complicated legal and administrative issues. Other deterrents include the 10-year withdrawal wait, which the panel suggests reducing to five, and legalities that vary

continued on page 2

The sky's their limit

Keen, cool and ready to make their mark, there's never been an AMI committee like our new Young Adult Group

ot yet a year old, they're already up and at it. The Young Adult Group (YAG), now pushing 15 members strong, was formed last September as an offshoot of the fundraising committee.

Chair Stephanie Kligman describes current and future committee members as most likely 18-35 years old, at school, recent graduates or young professionals moving up the career ladder. They all share a desire to be part of something big and meaningful. A good number have been recruited today's way, through social media. Thoroughly modern YAG is very much an e-player, with a Facebook page and a Twitter account.

Their goals are threefold: create corporate partnerships, raise awareness of stigma and work to counteract it, and raise funds in support of AMI.

The fundraising part is clear enough. Government funding and grants cover only a portion of our budget. The economic reality is that our programs will continue to need extra money to maintain their healthy growth. "Building partnerships," Kligman explains, "connects us to the corporate world and to sponsors who can help us mount successful events in the future."

As for stigma, YAG believes that laying low is no way to change attitudes. Why not meet the prejudice face-on and stare it down instead? Example: their first event, the Full Moon party, held June 14. The name was chosen because in more ignorant times people believed a full moon brought the "crazies" out. "Nobody celebrates mental illness,' says Kligman. "We wanted people to

have the self-confidence to say, 'I have an illness but I'm going to the party, I want to have fun and I want to be seen.'"

The evening was a triumph, complete with music, food, an open bar and body painting compliments of Annie Young Cosmetiques. Instead of tickets, YAG had

decided that partygoers would buy Full Moon t-shirts and wear them to the event. Through email and social media the public was invited to submit hashtags and a

contest was announced to pick a favorite. See The Unseen, the winning slogan, was printed on the t-shirt backs. "We chose it because mental illness is invisible, whereas those who suffer from it are visible and should be recognized," said Kligman. "See

The Unseen captures that idea."

Full Moon is just the first idea to come down YAG's pipeline. Now they're looking into Take Off The Mask as an event theme, the connection being that masks are common concealers in people's lives. Many of those living with mental illness routinely hide their situation behind a behavioral mask. A suggestion has also been made to organize a running group with its own special t-shirts. Researchers have found that running

helps increase serotonin levels, which may contribute to fighting depression.

YAG has a mixed mental-health membership. Some people have a diagnosed illness, others don't. It doesn't matter much to any of them. They're there because they believe in YAG's goals and want to help it succeed. The fact that friendships have sprung up since September just makes things all the better.

The welcome mat is still out at Young Adult Group and it's easy to join. Email **pam@amiquebec.org**. Or phone AMI's offices, **514-486-1448**, to learn when the committee meets next. It's usually every two or three weeks at AMI. □



Time to be proactive



Our Art for Charity fundraiser, held last April at the Liane and Danny Taran Gallery, attracted an enthusiastic crowd. Seen here, Miriam Byers (l) and Joanne Smith

Disability Savings Plan ... continued from page 1

according to different provincial and territorial jurisdictions.

The Senate panel proposes a more accessible plan and recommends the government increase its efforts to ensure that those wanting to participate are provided with any assistance they need. But why wait for all that to happen?

You can get the ball rolling far more quickly by speaking with an accountant or a lawyer. Aside from everything else you do to help your ill relative, the RDSP is too important an opportunity to ignore. $\hfill \Box$

"HELP ME TAKE BACK MYSELF"

See the whole person, not just the illness, patients ask of healthcare practitioners

ention Larry Davidson and many people who know his work automatically think recovery — but not recovery in the traditional sense. Davidson is a maverick in the world of mental healthcare, a psychology professor in the department of psychiatry at Yale who for years has been challenging the status quo and insisting that the mainstream approach to psychiatry and recovery has it all backwards.

A Low-Beer guest speaker in 2006, Davidson was in Montreal last April to speak

at a two-day conference hosted by the Douglas Institute, part of their series called *Moving Closer to People*.

His address, entitled *Reclaiming Personhood*, maintained that patients' right to live as a whole person should take priority and not be put on hold in deference to treatment for their illness. By and large, they currently don't have a choice, a reality that's especially true when the disorder is most severe and because mental illnesses are, as yet, incurable. Davidson challenged professionals to change their concept of recovery and, before anything else, work at helping their patients retrieve the personhood they once had.

"How do you help people 'relearn' to be a person?" he asked. "By treating them exactly that way — with compassion, courtesy and collaboration; by not perpetuating the culture and prac-



Davidson: rebel with a cause

tices which contributed to their losing their sense of being an individual in the first place; and by not making decisions for them, not doing things to or for them without asking or at least explaining."

Patients' comments like the ones that follow, liberally used in his presentation, shone a sharp light on some of the darkest aspects of living with a mental illness.

How it hurts

"I think I am dissolving. My mind feels like a sand castle with all the sand sliding away in the receding surf. This experience is much harder and weirder to describe than extreme fear or terror."

No more compass

"I can't direct my own attention. I no longer experience my actions as stemming from me. Even my thoughts seem to come from someone or somewhere else."

A nobody nowhere

"If other people act as if I am not here...if they make decisions on my behalf without my consent...if other people tell me I'll never get better and act as if I have nothing to offer, if they no longer treat me as a person...then perhaps I'll come to believe that myself."

Personhood

"To be able to participate in person-centered care, first you have to believe that you have the right to be a person." $\,$

Such palpable yearning to be a complete individual once more validates Davidson's confidence in recovery-oriented treatment: you can do it, we can help. \Box

Go online for your annual report

MI's 2013-14 annual report is available online at www.amiquebec.org/ar14. If you would like to receive a copy by mail, call us at 514-486-1448 (1-877-303-0264 outside Montreal) and we'll be happy to send you one.

Lights, camera ... continued from page 1

that sort of debate is the purpose of Snow's post-performance forums. It's where dialogue gets free rein and strategies for change can take root.

The right credentials

Snow trained as a theatre artist. While studying for his doctorate in theatre anthropology, he found himself watching ethnographic films of tribal people. He noticed that healing was a major preoccupation and a thought occurred: why couldn't theatre be used as a healing device? That sparked his interest in studying drama therapy and training as a drama therapist.

Personal reasons also prompted his decision. His father had bipolar disorder and suffered through some gravely serious episodes. For five years Snow worked in psychiatric rehabilitation of major mental illnesses at the Bronx Psychiatric Center. His consumer drama group there produced many plays, an extraordinary experience that Snow calls the essence of ethnodrama. "What made it so powerful was the authenticity, the realization that you were hearing the unvarnished truth from the closest possible source."

All of which brings Snow to AMI. He's determined that his next production will be about caregivers, a population he calls very underserved. "I know the enormous burden for families facing a mental illness and I want to do what I can to help," he says.

Snow would recruit 10, maybe 12 caregiver participants. They'd all meet once every week or two for roughly three months, either at Concordia or a place of AMI's choice, somewhere clean, comfortable and easy to access. During those weeks they'd tell their stories, their lived experi-

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Annual general meeting

AMI AT 37: STRONG, RESPONSIVE, RESPECTED

embers attending our annual general meeting in early June were treated to an impressive health report. After 37 years AMI is at the top of its game.

We're offering more programs and services than ever to Montrealers and people living beyond the city — some 4,000 program participants in the last year.

We're launching new programs such as borderline personality disorder and coping skills for caregivers and exploring new initiatives to attract more people. Webinars were the latest outreach addition this past year.

Fundraising, essential in these economic times, has enhanced our public profile while increasing awareness of mental illness and contributing in the nicest way yet to our bottom line. We are seen as an authoritative voice in the healthcare sector and a reliable source of information. Last year our website registered close to 30,500 visits — the highest ever.

Following the awards presentation, Steven Snow, who heads Concordia University's department of creative arts therapies, discussed his use of therapeutic theatre, in which he stages plays based on the stories participants tell. It's something special, exciting and he wants AMI caregivers to be part of his next project. Read the full account on page 1.

Will AMI at 38 have an even better year? No reason why not. □



"I have every reason to be enthusiastic about AMI," summed up **President Jean Claude Benitah** in his opening remarks



The Monty Berger Award for Exemplary Service was presented to Francine Waters, our program coordinator and counselor, for her 13 years of caring and dedication

Board of Directors 2014-2015



Executive Committee, l-r: Joanne Smith, secretary; Annie Young, immediate past president; Jean Claude Benitah, president; Anna Beth Doyle, vice president; Norman Segalowitz, treasurer

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Brenda Cormier was chosen **Volunteer of the Year** for her generous contribution of time and effort



In acknowledgement of careers marked by generosity and humanity, **Drs. Gerard Pierre Louis** (l), St. Mary's Hospital, and **Luis Vacaflor**, Montreal General Hospital, were honored with **Exemplary Psychiatrist Awards**



Tom Caplan (r) accepted the AMI-Québec Award for Exemplary Service for his numerous commitments to family well-being. Bob Harris (centre), alongside presenter Benitah, was an Extra Mile Award recipient for his efforts in helping people with mental illness to succeed in the workplace. Sophie Glorieux (not pictured), whose candor about her own recovery helps fight stigma, was another Extra Mile Award winner



Steven Snow, Concordia professor of drama therapy, explains how drama can be the catalyst that turns pain into art

SUMMER 2014

For details visit amiquebec.org/programs-support

SUPPORT GROUPS

Mondays 7:00pm 4333 Côte Ste-Catherine Road unless otherwise indicated. No registration necessary.

FAMILY for relatives and friends only

July 7, 21; August 4, 18; September 8, 15, 22

SIBLINGS AND ADULT CHILDREN for relatives only

July 21; August 18; September 15

BIPOLAR DISORDER for family, friends and people living with mental illness

July 21; August 18; September 22

DEPRESSION for family, friends and people living with mental illness

July 7; August 4; September 8

OBSESSIVE COMPULSIVE DISORDER

for family, friends and people living with mental illness July 21; August 18; September 15

HOARDING GROUP (in collaboration with Quebec OCD Foundation) for family, friends and people living with mental illness

July 7; August 4; September 22

KALEIDOSCOPE for people living with mental illness

July 21; August 18; September 15

ANXIETY for family, friends and people living with mental illness

July 7; August 4; September 8

SOUTH SHORE for relatives and friends

Wednesdays 6:30pm

Greenfield Park Baptist Church, 598 Bellevue North, Greenfield Park

July 9, 23; August 6, 20; September 3, 17

LIFELINE for people living with mental illness

Last Tuesday of the month 1:30-2:30pm

Alternative Centregens, 5770 Auteuil, Brossard

BOARD MEETINGS

Tuesdays 7:00pm at AMI July 29, September 9

WHAT'S IN A NAME?

There's talk of renaming schizophrenia. But will the stigma still be there?

Chizophrenia has a serious problem. No other mental illness carries with it such a heavy load of prejudice and stigma. The misinformed, knee-jerk association is with danger, violence and fear. Even the name is a misnomer. Schizophrenia has nothing to do with "split personality," as its coiner, psychiatrist Eugen Bleuler, assumed over a century ago, and everything to do with a mind split from reality or psychosis.

There's a point of view making the rounds in recent years that argues for a new name for schizophrenia. It would go a long way towards eradicating the stigma, the rationale goes.

In 2002, Japan's Society of Psychiatry and Neurology changed the term from "mind-split disease" to "integration disorder." A follow-up survey reported that the new name was being used for 78 percent of diagnoses in public documents. It may or may not be cause and effect, but a 2012 study of the general public found that people showed a positive attitude towards treatment in cases where they or a family member had been diagnosed with schizophrenia. That's significant in a country with a unique shame culture, where disabilities are considered shameful and are often hidden by families with affected relatives.

Aadt Kliyn and Bill George of the Dutch Association of and for People with a Psychotic Vulnerability offered Psychosis Susceptibility Syndrome as their name-change of choice; it has been officially approved by the Association. However, neither the American Psychiatric Association nor the World Health Organization, which were both consulted on the matter, has gone along with the change. Both the Netherlands and professionals internationally have withheld their endorsement.

A change of name is important not just for the sake of change, but because it can provide an image-rebranding opportunity. People with Down syndrome are seen to be more respected now than they were when they were called "Mongols."

Some feel that the name schizophrenia has outlived its usefulness, but the problem is not so much whether to replace it as what to replace it with. Relabeling may not do much to solve any scientific and clinical limitations that exist. Nor will it be effective against stigma, which is largely media-stoked and emotionally based on half-truths.

We'd like to know what you think. Should schizophrenia's name be changed? And what should it be changed to? Send your comments to **info@amiquebec.org**. We'll publish our findings in a future issue of *Share&Care*. □

STAY INFORMED

Our website is updated regularly with the latest news about our programs, services and upcoming events. Get the good habit of checking our homepage often. There's always something happening. www.amiquebec.org.

Elizabeth Tremain, past president and director emeritus of the AMI-Québec board of directors, passed away on June 3. AMI remembers Elizabeth's untiring efforts on behalf of people with mental illness and their families, and extends heartfelt sympathy to her family.



Meaningful films for caregivers

A film festival and two oldies-butgoodies offer a bonanza of viewing pleasure for movie buffs

A return for Au Contraire

Partners UpHouse and the Montreal Museum of Fine Arts are bringing back this film festival dedicated to increasing awareness of mental illness. On October 24, AMI's sponsored night, the documentary *Unlisted: a story of schizophrenia* explores the relationship between a daughter and her ill father. A panel with the daughter-producer will follow. Ticket details to come — check our website. And circle October 24 on your calendar now.

The Soloist (2009)

Based on the true story of musician Nathaniel Ayers, the film follows journalist Steve Lopez (Robert Downey Jr.) as he befriends Ayers (Jamie Foxx), whose diagnosis of schizophrenia has led to his being homeless.

The two begin a journey during which Ayers slowly regains some of his former prestige and sanity, while Lopez acquires insight and understanding into what living with mental illness really means.

Benny and Joon (1993)

The film follows a brother and sister (Aidan Quinn and Mary Stuart Masterson) as they face the challenges of mental illness. Joon pursues independence (including dating a character played by Johnny Depp), while all three learn the true meaning behind love, family and happiness. \square

Information on the two above films from SZ Magazine, spring 2014.

Blood test identifies risk of depression

The first biological test for clinical depression has been developed at Cambridge University in England. Scientists there have established a link between the risk of depression and excessive levels of the stress hormone cortisol.

When researchers measured cortisol in teenage boys, they found that those with high levels of the hormone along with mild depression symptoms were up to 14 times more likely to suffer clinical depression later in life compared to teens with low or normal cortisol levels.

The testing was carried out on 1,858 teenagers, both boys and girls, ages 12 to 19. Although women are twice as likely to develop depression during their lifetime, the Cambridge study proved to be little help in determining the girls' risk. Those with similarly elevated cortisol levels to the boys were found to be only four times more likely to develop the illness.

One theory for the variance is that women naturally have a higher cortisol level than men. There may also be gender differences in how depression develops.

The study is an important first step. If, as it suggests, depression is caused by a chemical imbalance, it means that in the future doctors could definitively identify the mood disorder with a simple blood test instead of having to rely exclusively on patient consultation for a diagnosis. This would enable treatment to begin at an earlier stage. Up to now there has been no biological test to spot major depression, which affects one in six people at some point in their lives. \square

TRIBUTES & MEMORIALS

In honor of Colombe Daudelin **Cheryl-Lynn Roberts**

In honor of Ted and Adry Chazin Rita Chazin

In honor of Danny Berg Keila and Billy Finkelstein

In honor of Rona Katz-Kucer

Linda Dennick

In honor of Howard Richman Linda Dennick

In honor of Norma Nutkevitch Lynn Nulman

In honor of Barbara and Jack Singer Lynn Nulman

In honor of Peggy Stark and Seymour **Coviensky**

Lynn Nulman

In honor of Rhonda Nutkevitch

Lynn Nulman

In memory of Monty Berger

Kay Simpson

In memory of May Gruman

Kay Simpson

In memory of Anita Miller

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In memory of Evelyn Ortenberg

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AMI-Québec Donation & Membership Form

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Lights, camera ... continued from page 3

ence of being caregivers. Snow would develop a script based on the collected data. "For the group it's really like play, often very expressive play, and I can promise that as artistic expression it's a lot of fun," he says.

Snow will subsequently fashion the material into a script and show it to the group for their opinions. Is it true to their experience? Does he have their permission to proceed? Confidentiality is key and nobody's name is used without permission. Working with AMI, Snow will probably choose professional actors to turn his script into a powerful drama.

The final step is staging the play for the caregivers and also healthcare professionals, who would all meet at the post-performance forum to find answers to important questions: How to improve caregivers' resilience? What about burnout? What do caregivers really need?

"Drama therapy is a powerful tool for self-healing," says Snow. "Working with AMI caregivers we could do something really amazing that would benefit them, help the community to better understand and corroborate AMI's mandate to serve caregivers."

An information session with Snow will be held in the fall. If you are interested, call AMI at **514-486-1448** or email **info@amiquebec.org** to put your name on the list. □



This issue of Share&Care has been made possible by an educational grant from Janssen-Ortho.

<u>ami</u>québec

Agir contre la maladie mentale Action on mental illness

AMI-Québec, a grassroots organization, is committed to helping family caregivers*
manage the effects of mental illness through support, education, guidance
and advocacy. By promoting understanding, we work to dispel the stigma still
surrounding mental illness, thereby helping to create communities that offer new
hope for meaningful lives.

* Family caregivers are those in the circle of care, including family members and other significant people, who provide unpaid support to a person living with mental illness.

Jean Claude Benitah, President Anna Beth Doyle, Vice President Joanne Smith, Secretary Norman Segalowitz, Treasurer Annie Young, Immediate Past President Ella Amir, Executive Director



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Ella Amir, Executive Editor Bryna Feingold, Editor Liane Keightley, Designer

Articles and comments are invited. Anonymity will be respected if requested. Guest articles reflect the opinions of the authors and do not necessarily reflect the views of AMI-Québec.

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Member of La Fédération des familles et amis de la personne atteinte de maladie mentale (Québec)