NSSS ADVOCACY BULLETIN
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Cosmetic anti-stigma campaigns miss the point

Schizophrenia societies are pioneers in anti-stigma work in Canada, courageously taking schizophrenia, the most disabling of mental illnesses, out of the closet, in the 1980s when their societies were formed.

Simply creating a schizophrenia society and calling oneself the Friends of Schizophrenics was a bold act in those days.

We ourselves, the North Shore Schizophrenia Society, do wide-ranging public education and anti-stigma work, recognizing its importance.

Why, then, are we so troubled by some of the much-touted anti-stigma campaigns now underway under the aegis of large and well-financed organizations like the Mental Health Commission of Canada and the Bell Canada mental health initiative?

It comes down to two basic factors.

First, in the attempt to destigmatize those with a mental illness and to promote a cheerful, upbeat message about recovery, these campaigns often gloss over just how tough those illnesses can be and what's needed most in helping those who are ill.

In doing so they shortchange understanding.

Second, all the attention focused on the need to combat stigma misses the point of what the most crucial issues for the seriously mentally ill are, issues like the need for treatment. The anti-stigma campaigns function instead as a distraction.

Grassroots education work faces mental illness openly

Effective education work doesn't shy away from difficult subjects and details. It goes into them openly and honestly instead. Only by doing so can it help generate sufficient understanding.

NSSS's awareness and education programs keep this in mind. They involve both family members, with hands-on experience trying to help their loved ones, and people with schizophrenia or bipolar disorder in particular who have fought difficult battles with their illness. Sometimes they present together.

The presentations are open and frank accounts of people's lives and experiences, detailing – depending on the individual story – severe psychotic symptoms, suicide attempts, substance abuse, relapses, years moving in and out of the mental health system and group homes, and the uneven route to gaining insight and stability.

Far from minimizing the illness, the presentations focus on it and, in so doing, broaden and deepen understanding. The openness also makes the stories all the more inspiring because they show how far back from the depths of illness people can come.

While the society's Family Support Centre and its programs cover the whole range of serious mental illness – bipolar disorder, depression, and anxiety disorders as well as schizophrenia – NSSS at the same time tries to ensure that schizophrenia itself doesn't become marginalized.

Its banner, used in community parades and elsewhere, prominently displays the name of the society. The name and banner, for an illness that in the past was the most stigmatized of them all, underscore the point that mental illness is nothing to be ashamed of or feel guilty about.

Combating the stigma surrounding schizophrenia in particular has extra impact for combating stigma about mental illness in general.

Downplaying severe mental illnesses in anti-stigma campaigns, to the point of marginalizing them or not discussing them at all, on the other hand, is surrendering to stigma – in effect reinforcing stigma rather than combating it

The Mental Health Commission of Canada has become notorious for going off track in this way. In its draft national strategy, it omitted even mentioning schizophrenia or bipolar disorder, effectively putting them back in the closet where they used to be.

Honest portrayals are out, too. In rejecting a documentary on an art program that gives viewers insight into schizophrenia, a commission representative explained they were focusing on hope and recovery instead. The goal of his program, Opening Minds, was to reduce stigma and discrimination, he went on. It appears that frank portrayals of what it's like to be ill are too much of a downer for them.

The producer of the documentary, meanwhile, thought his video was precisely about hope and recovery.

Cosmetic approaches undermine impact of anti-stigma efforts

The rationale for the commission's strategy isn't a mystery. They calculate that by saying less about severity and difficulties, especially anything associated with psychosis or headline incidents of violence, they'll be creating a general acceptance of mental illness and a more positive outlook about recovery.

The end effect, though, for serious mental illness, is indirectly to demonize it because it's not pretty. It's difficult illness needing treatment, where gaining stability and restoring a sense of self is often a long and tortuous path, and levels of recovery vary.

The opportunity to provide the public with necessary understanding is also lost – not at all a good way of reducing stigma.

The commission isn't the only offender. In a capital campaign to raise money for a new psychiatric acute care building, the Lions Gate Hospital Foundation in North Vancouver, in its literature, had stories about depression and bipolar disorder, but not about schizophrenia.

It was left to NSSS to point out that although the prevalence of schizophrenia may be less than with the other two illnesses, the highest use of acute-

care beds is for schizophrenia, because of greater severity in its acute phase and hence more than average admissions to hospital and longer hospital stays.

And the capital campaign, after all, was for an acute-care building.

Not mentioning something as major as schizophrenia was appalling to begin with.

The Bell Canada "Let's talk" mental health initiative, featuring Olympic athlete Clara Hughes, suffers from somewhat the same kind of distortion. In a "Start a Conversation" feature, it lists the symptoms of depression and anxiety disorders, but not of bipolar disorder or schizophrenia. Bipolar disorder isn't even mentioned in passing.

Nothing so disturbing as "delusion" or "hallucination" is allowed to taint the cosmetic picture.

Stigma isn't most pressing problem

Anti-stigma initiatives are currently all the rage and are being given a big profile and large dollops of money.

The leading impetus behind the creation of the Mental Health Commission of Canada was to remove the stigma associated with mental illness. Opening Minds, their anti-stigma program, is at the top of the list of their initiatives.

Fighting stigma is also a major part of the Bell Canada initiative. They've even gone as far as funding the "world's first" chair in anti-stigma research, at Queen's University in Kingston. The claim is that a lot of people don't get the care they need because they are afraid to ask for help.

NSSS watches this seeming preoccupation with stigma in amazement. Notwithstanding its own, extensive education work, combating stigma has never been the leading issue for it.

What counts far more is getting people who are seriously deteriorating into hospital and stabilized, and all the other things that go with it.

This includes the proactive use of involuntary admission where appropriate; family involvement as an integral part of the treatment team; the necessary sharing of clinical information with family members; proper discharge planning and follow-through; intensive community treatment programs; timely and dedicated outreach to those in difficulty; adequate acute-care beds and tertiary and refractory facilities….

It's a long, long list**,** with other items to be added to it as well. Combating stigma, while useful, comes after all of these other matters, far down the list.

It's not stigma or shame that prevents somebody who is hearing voices, or someone who is manic, from asking for help. It's lack of insight into their illness (anosognosia).

It's not stigma that triggers suicide. It's the impact of the illness, with inadequacies in mental health services, in allowing people to deteriorate, a contributing factor.

If a man, driven by his delusions, jumps off a bridge to his death, being free of the fear of stigma doesn't help him. Nor does it help somebody who is so delusional and paranoid that they end up committing homicide.

In NSSS's support and advocacy work, stigma hardly comes up.

What's most on the minds of people who come to the Centre for help is trying to get a grip on a situation that is overwhelming them and, if they're faced with a crisis, trying to get their ill relative into hospital.

Against this backdrop of critical need, the exaggerated hoopla about fighting stigma is a little bizarre.

Not giving treatment priority ironically increases stigma

Not facing the reality of severe mental illness squarely, not focusing first of all on the most seriously ill, not making treatment and support the leading priority, not allocating the biggest part of one's educational and publicity resources to making that happen…all this ironically, by omission, increases stigma.

Madness in the streets, after all, is not a pretty sight. Think of the Downtown Eastside in Vancouver or similar neighbourhoods in many other cities across North America. What's most disturbing is that even with deinstitutionalization it need not be that way. Intensive outreach, and treatment and support, work.

Violence arising from untreated psychosis generates even more stigma.

One of the survey findings that the anti-stigma initiatives like to cite is that, according to a 2008 survey, 25 per cent of Canadians are afraid of being around someone who suffers from serious mental illness. This is put forward as simply shocking, but what contributes to this attitude?

Those with schizophrenia who follow their treatment program and take medication are no more violent, probably less violent, than the rest of us. Untreated, though, is a different matter. Often driven by delusions and hallucinations, they're six times more likely to commit a violent act.

A single incident of psychosis-driven homicide can be so graphic that just by itself it can undermine the most sophisticated and expensive of anti-stigma efforts.

If the wayward Mental Health Commission and if Bell Canada were truly serious about eliminating stigma, they would be looking into all the tragedies that have occurred because of untreated illness, identify what went wrong – in particular the failure to use involuntary admission although it was required – and make a big point that action needs to be taken.

This would also be their leading initiative, in time, energy and dollars, and in the kinds of appointments they make to their boards and committees.

Eminent U.S. psychiatrist and author E. Fuller Torrey, in a study published in the *Schizophrenia Bulletin* in 2011, documents how the increase in violent acts by the mentally ill in the last half century has contributed to stigma, and establishes as well that most such episodes are associated with a failure to treat the mentally ill persons involved. The article was entitled, "Stigma and violence: isn't it time to connect the dots?"

Those dwelling on stigma and organizing big campaigns to combat it, in a vacuum, have yet to connect the dots.

FEEDBACK WELCOME

We welcome your comments. Please call us at 604-926-0856 or email us at advocacy@northshoreschizophrenia.org.

COMING UP IN THE NSSS ADVOCACY BULLETIN

Small failures in mental health services and clinical practice can mean large setbacks for the mentally ill and punishing stress for their families. Watch for the March issue.