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'For many of us, it's ... a calling'

The first time Senator Michael Kirby was exposed to Canada's mental health system, he figured he'd picked a bad place on a bad day. "I thought the awful service my relative was receiving was unique," he recalled.

Now he knows better. As chair of the Senate social affairs committee, Kirby has heard hundreds of stories worse than his.

He has been moved to tears, shocked, enraged and ashamed. "The situation is much worse than I thought it ever could have been."

The committee is midway through a three-year study of mental health and mental illness in Canada. This week, it issued its interim report.

Its findings will come as no surprise to those living with mental illness.

They are miserably aware that Canada's mental health system is fragmented, underfunded and almost impossible to navigate. They know that society uses comforting euphemisms - cognitive impairment, mood disorder, developmental difficulty - to avoid talking openly about mental illness. They live with the reality that their sickness could land them in jail, a homeless shelter, or on the streets.

The committee's job will be to open the eyes of the rest of the population.

It won't be easy. Some people prefer to remain safely ignorant. Some are reluctant to discard their crude stereotypes. Some are afraid to talk about disorders of the brain.

But Kirby and his 11 Senate colleagues are determined to pull mental illness out of the shadows. Most have had a family experience with the psychiatric system. "For many of us, it's become a calling rather than a standard policy review," Kirby explained.

His deputy chair, renowned heart surgeon Wilbert Keon, added a professional perspective. "This just has to be done. We are the only G-8 country without a mental health strategy."

The committee will hit the road in February, asking Canadians to help it draft such a strategy. The issues and options laid out in this week's interim report will serve as a framework.

Here are its main themes:

Building a coherent system:

"The committee is convinced that the status quo is not an option."

Kirby and his colleagues want the public's advice on how to revamp mental health services to fit the needs of patients, rather than the structures and schedules of bureaucrats and medical authorities.

Putting help within reach:

"A majority of Canadians suffering from mental disorders still do not seek and receive professional help."

The senators want to know how to reach out to the 68 per cent of individuals with mental health problems who never see a health-care professional. They wonder if the primary impediment is a lack of facilities or a fear of acknowledging mental illness.

De-stigmatizing mental illness:

"Has the word stigma become a polite linguistic way of justifying discrimination?"

The committee wants to know what kind of public awareness campaign it would take to convince Canadians that mental health is as important as physical health. It wants to make it unthinkable to deny individuals with mental illness the right to housing, employment, insurance, education and a fair trial.

Improving workplace awareness:

"An organization's internal culture can make a huge difference in helping employees live with mental illness."

Although a few companies take an enlightened approach to mental disorders, most employers, managers and insurers are either grudging or ham-handed in offering support. The committee wants to know what incentives or sanctions it would take to get employers to treat mental illness as humanely as other disabilities.

Catching mental illness in kids:

"Early intervention is fundamental to arrest progression towards full-blown disease"

The committee wants to know whether mental health screening should be done in schools to detect the 15 per cent of youngsters with mental illness, and if so, at what stage.

Assisting the gatekeepers:

"Primary health care providers may lack sufficient knowledge, skills and financial incentives to meet the needs of patients with mental illness."

The senators want to know how family doctors, who are already coping with huge patient loads, can be trained and motivated to treat individuals with time-consuming mental disorders.

Showing federal leadership:

"Canada lacks national leadership in mental health, mental illness and addiction, a serious deficiency that, in the view of many, has left a very large void."

While conscious that the delivery of health services is a provincial responsibility (except to First Nations, veterans, members of the Armed Forces and RCMP and federal inmates), the committee wants to know what role Ottawa could play in moving mental health from the periphery of medicare to the mainstream.

The committee intends to table its final report in roughly a year. It will be the first time any parliamentary body has taken a comprehensive look at the mental health system.

"Our job is get the story out and make our message compelling enough that people will coalesce behind it," Kirby said. "We've got to break through people's reserve."

"It's a Herculean task," Keon said.

The committee will need all the help it can get. It is asking Canadians who have hidden their mental illness to speak out bravely. It is asking their fellow citizens to listen compassionately.

(The full report is available at www.senate-senat.ca/social.asp).

Carol Goar's column appears Monday, Wednesday and Friday.

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Government wants mental illness stories

Memo to: All Canadians touched by mental illness and addiction.

From: Your government.

Please tell us your stories.

Tell us how we can make things better. We know you fear telling your stories. But we need you to be brave.

This remarkable plea went out to Canadians this week when a federal committee posted an online questionnaire seeking input from the one in five Canadians who have suffered because of mental illness or addiction.

Senator Michael Kirby says the committee posted the online survey because the fear and stigma associated with addiction or mental illness are so strong that an important piece of the puzzle - the personal stories - might never be heard.

The survey is part of an ongoing review of mental health services in Canada. After 18 months, with the first phase of the review completed, the committee is heading out for cross-country hearings. In a report this week, the Senate standing committee said mental health services are fragmented and ineffective. Stigma and discrimination associated with mental illness and addiction are largely responsible for the system's failings, it says. There are no data about how many are affected by mental illness, but estimates say one in five Canadian adults (about 4.5 million individuals) experience mental illness in their lifetime.

Kirby wants to hear: "What is it you really need to live your life? To feel good about yourself?"

The committee needs to hear directly from what he calls "the most important people" - ordinary Canadians. Their stories will point the way to workable solutions, Kirby says.

The questionnaire is posted at www.senate-senat.ca/SOCIAL.asp. Click French or English, then select the link. Respondents' privacy will be respected. There is no need to give your full name.

Patients' groups have lauded the move.

Phil Upshall of the Mood Disorders Society of Canada says it is a "visionary" step.

Kirby met with advocacy groups and they have pledged to encourage people to answer the survey.

"Let's flood them (with) everything we want to say," says Karen Liberman, of the Mood Disorders Association of Ontario.

Here are some stories from the report.

Loise has bipolar disorder

Ten years ago, following the sudden death of my partner in life, I had an episode of manic psychosis. You feel you could save the world during that period. I had an episode, which lasted six months and ended with a suicide attempt. That was followed by four years of depression.

For years, I had to tell and repeat my life story (to doctors) . . . the traumas, the painful things, and each time I had to start all over from scratch ... It was extremely painful.

Ronald's wife has schizophrenia

She believes she's good for nothing and a failure. I was alone. I had no help. How I managed to get through it all, I don't know. It was very hard on the children.

Murray's son has autism

My son is not classically autistic. He can speak; he can read; he graduated from high school. We sensed that school was becoming more stressful for Adam as he became older.

He would get so angry that he would break windows and pull out light fixtures. He was admitted (to hospital) and diagnosed incorrectly with bipolar disorder. It is not much better today.

Kirby was asked to chair the review after the Romanow report called mental health the "orphan" of Canadian health care. The committee will be in Toronto from Feb. 15 to 17, and then will hold cross-country hearings until the spring. Kirby hopes the government committee can "bring Canadians together to debate, find a plan for change and rally around it."

Stigma is the biggest roadblock, he says. People fault the media - news and entertainment - with creating stereotypes and stigma about people with mental illness, the report says. Unless this changes, according to Kirby, people with mental illness and addiction will face an uphill battle.

Stereotypes typically show them as "psychotic, unemployed, transient, and dangerous - not as productive members of a family or community," the report says, or as "homicidal maniacs who need to be feared."

More than 70 per cent of characters with mental illness on prime time television dramas are violent; and more than a fifth are killers, the report says.

Yet Health Canada has "no compelling scientific evidence to suggest that mental illness causes violence," it says.

Evidence does suggest people who don't get help, or who also abuse drugs or alcohol, are more likely to be violent, but are at more danger from self harm.

Rachel Manning, a Toronto woman, with bipolar mood disorder, says she wants to break down stigma. The idea that people with mental illness are violent is one of the most damaging stereotypes, she says.

Manning appears in a TVO documentary Sunday at 10 p.m. about her work in a play staged at the Madness and Arts World Festival at Harbour front last year.

She says stereotypes are dehumanizing and recalls how once, when she was agitated and sent to hospital, six people held her down and "shoved a syringe into me."

"There was no need - but I wasn't a person to them at that time," she says.

Today she has effective medication and is working to rebuild her career and change people's perceptions.