Lived experience leads the way with peer support project

Louise Elliott

Stephane Grenier remembers the turning point. After struggling for years with post-traumatic stress disorder, the lieutenant-colonel in the Canadian military says a sympathetic boss made the difference.

"My chief of staff noticed that things were bizarre," he says. "He pulled me into his office and said, 'Look, you've got a good reputation, but for some reason the guy that's here is not the guy I've read up on. If you need time off to get better, take it.'"

For Grenier, that gesture gave him permission to recover from the effects of the trauma he had experienced during a tour of duty in Rwanda four years earlier.

"That set the stage, that simple thing," he said. "It's like the antidote to stigma, and although he was my boss, that social support made everything gel."

Little did Grenier know that experience would set the stage for so much more.

After he gained some recovery, Grenier set about trying to "clone" his experience for other soldiers experiencing mental illness, who were suffering as he had for years – in silence and isolation.

"When I started getting better in 1999, I started reading everything I could (about PTSD)," he says. "Social support kept being mentioned, but any time it was mentioned, normally it was at the end of a chapter or book. Then I started asking, 'How come none of the studies is giving us a blueprint on how to replicate (social support)? If it's that important why aren't we doing anything about it?"

Grenier set to work. He formed a successful peer support program within the military for soldiers suffering from operational stress injuries. Called the Operational Stress Injury Social Support (OSISS) program, it now provides a backbone of understanding and practical help to soldiers across Canada who suffer from stress injuries, and their families. The program -- which relies on soldiers helping other soldiers -- celebrates its 10th anniversary this year.

Now, Grenier is trying to clone that success on an even larger scale. He's spearheading a new peer support project under the auspices of the Mental Health Commission of Canada, with the goal of creating a curriculum, a set of standards of practice, and an accreditation system that will train and accredit peer support workers across the country. The initiative will contain several pilot projects within Canadian workplaces and mental health settings. And it will include the participation of people with lived experience with mental illness from start to finish.

Grenier is aware the project will require leadership on the part of businesses and individuals. But he believes it has the potential to seriously do battle with the stigma surrounding mental illness.

"If society grabs the bull by the horns, and says, 'It's ok, you're human,' that allows the stigma to lift," says Grenier.

Many theories

There are many theories about what peer support is, and how it works. But at its most basic, says Dr. David Goldbloom, vice-chair of the Mental Health Commission of Canada, it relieves the sense of isolation and shame.

"My informed hunch is that it works for a couple of reasons. It does not involve the inherent power imbalance that exists between health care providers and health care recipients," says Goldbloom, who is also a longtime professor of psychiatry at the University of Toronto and the senior medical adviser for education and public affairs at the Centre for Addiction and Mental Health.

"And the second reason is the powerful sense of identification with a peer support worker – somebody who has been there. Somebody who has experienced whatever the person who is receiving the support is going through."

Goldbloom has high hopes for what the project can achieve by setting standards for peer support as a profession. He says formal peer support will never take the place of informal peer support, but rather, complement what happens naturally while giving more credibility to the work.

"(Formal peer support) is actually a recognition by the health care system that this is a valued role worthy of remuneration that becomes part of a complete wraparound of services that are provided."

Setting standards is all part of a move toward greater credibility. And Goldbloom thinks this project has significant potential not only to break down stigma in society generally, but within the clinical professions.

"I think it can help in a very significant way to erode some of the stigma that exists among mental health professionals," he says. "It can break down a bit of the 'we-they' dichotomy by working alongside people who are very openly acknowledging their mental illness and using their experience to help other people."

Lack of consistency

Roy Muise has been a leader in peer support in Canada for over a decade. A peer support specialist in Dartmouth, N.S., Muise is one of the first Canadians to take part in formal peer support training – in Georgia – in 2004.

"I've heard people talk about life-altering experiences," he says. "After I went there I learned what that meant."

Muise, who spent 30 years working in retail before mental illness ended that career, has been preaching the importance of developing standards for peer support for years. He believes Nova Scotia is ahead of the curve. For some time now, he has been developing a peer support training program through the non-profit organization, the Self-Help Connection.

This summer, Grenier and his colleagues consulted face-to-face with Muise, along with another 110 peer support workers and experts across the country, and drew them into the national project. Muise explains why national standards of practice, and an accreditation system, are so important.

"We all want to be on the same page," he says. "Part of the problem in Canada when it comes to mental health services is that they've been totally fragmented. If we're going to have a new service, let's have standards so that it's the same right across the country."

Game plan

Grenier and his steering committee completed the consultation phase of their project in January. In total they consulted more than 600 peer support workers and other mental health experts across the country, either in-person or online. More than 300 have now registered with the project to help shape its future.

"There was an impressive amount of knowledge and it was amazing how consistent people think things should be," he said. In fact the only point of divergence was that the mental health clinicians who responded predicted even better outcomes from peer support than the peer support workers themselves, he says with a chuckle. Peer support workers, it seems, are selling themselves a bit short.

The next phase, recruitment, is now underway. The project is seeking about a dozen partners in order to move ahead in three major areas: developing standards of practice, developing the training curriculum, and ensuring sound program evaluation or research as the project proceeds.

"I am convinced we can recruit at least a dozen visionary corporate leaders who will want to pioneer the quest," says Grenier. Those leaders will be drawn from corporations as well as medical systems or hospitals willing to put some research dollars up front, or the equivalent in research capacity. Parts of the project will be embedded in the health care system, and other parts in companies themselves where mental illness has had an impact on the bottom line.

Grenier acknowledges one of the biggest challenges is getting employers such as companies and organizations to invest.

"I think the hard piece is our ability to convince employers to look at the medium- to long-term, not the short-term," he says. "(In the corporate world) we seem to be consumed with how to produce trinkets by the end of the day. But when it comes to human healing it requires more time and patience."

Still, the numbers should spur any reluctant employers to action. Mental illness is believed to cost the economy some $51 billion a year in lost productivity. And that sum continues to rise despite employers pouring money into medical benefits and employee assistance programs. Something isn't working, and the project leaders believe the missing piece could be peer support.

Peer support is not a substitute for medical treatment, Grenier notes. In fact, one of the unexpected benefits of the military's peer support program was treatment compliance. The new project will research that phenomenon through a rigorous concurrent study of results – another first in Canada.

“We’d like to validate the system we’ve developed,” Grenier says.

Validation needed

Such validation through research is sorely needed, says Jayne Barker, the vice-president of research initiatives and mental health strategy for the Mental Health Commission.

“Peer support doesn’t always get the recognition it deserves, in my view,” she says, adding that the solid research framework that’s now being designed by the peer support project will help change that.

“When it comes to making funding choices, government and other funders don’t invest a lot of money in peer support,” she says. “I think part of the reason is because until now, there hasn’t been a way in Canada for them to have some assurance (as to) what they’re purchasing.”

Barker spearheaded the creation of a mental health plan for children and youth in British Columbia, the first of its kind in Canada. She argues an accreditation mechanism is essential.

“As with hospital accreditation, you know what you’re getting,” she says. “It’s a particular standard and includes particular things. So that peer support can take its rightful place in the continuum of care.”
Originally a public health nurse, Barker first became convinced of the value of peer support as a stabilizing force when she saw it at work in a clubhouse for the mentally ill in Powell River, B.C.

“In my small community we didn’t have the resources for a staff,” she says. “So we were able with a small amount of funding to make it work. Peers would work there and did a fabulous job. From a common-sense perspective it makes sense.”

When it comes to convincing employers and the government of the value of peer support, Barker is optimistic due to a proliferation of legal challenges that have taken place recently between employers and their staff.

“Those kinds of settlements have really increased over the past several years,” she says.

“Workplaces are suddenly wanting to pay attention to the mental health needs of their staff. Peer support is another way they can do that.”

Peer support doesn’t just reinforce other aspects of the mental health system, Barker says. It also can also help keep people on the job as they recover.

“Without that kind of support, people often feel they have to leave,” she says. “Peer support can be quite normalizing.”

Barker envisions pilot projects in several major workplaces over the next three years.

“There will be lots of learning we can then make available to other workplaces, so when they go to do this, they’ve have this model.”

Area of debate

Another challenge of which project leaders are well aware is the question of whether accreditation will reduce the effectiveness of peer support.

It’s a debate Grenier is eager to have.

“The challenge is, how do we reconcile two realities: the need for more structure and the organic nature of peer support work?”

Grenier is dead set against making peer support just “another structured intervention.”

“The day a peer support worker is looking at his watch when supporting someine is the day peer support should stop,” he says.

Some proponents of peer support take the purist route: they don’t believe you can create the same equal footing between the supporter and supported if peer workers are accredited.

Grenier’s view is less black and white, but he understands the concern. He believes the project’s insistence on an ongoing consultation with workers and people living with mental illness will help find the right balance.

He also notes that setting rigorous standards for the profession could also affect research outcomes.

“When building a trusting relationship, it’s hard for the peer support worker to apply standard research methods,” he says. “It’s complicated because there’s no structure to where peer support happens. It doesn’t happen in an office for 60 minutes. It takes many many different shapes.”

For Dr. David Goldbloom, accreditation doesn’t have to be an either-or proposition.

“(Formal peer support) will not undermine informal peer support,” he says. “If you are going to recognize something as being important and worthy of scrutiny, then it can’t be catch-as-catch-can.”

Roy Muise, who’s done peer support for a decade, remembers a time when it didn’t even have a name. He recalls the joke his instructor in Georgia used to tell to drive her point home.

“She basically warned everybody if she found out they were acting like a professional while they were at work, they were in trouble.”

He adds that the need to accredit peer support workers derives partly from the fact that not everyone is cut out for it.

“Just because you are living with a mental health issue doesn’t mean you would make a good peer support worker. That’s the bottom line.”

Goldbloom warns that the creation of standards of practice should not be exclusionary.

“First of all my hopes are that it becomes an enabling rather than a restricting standard’ he says. “In other words, that it does not say to the vast majority of people who have experienced mental illness, ‘I’m sorry, you do not have the necessary skills to become a brand certified peer support worker.’ But rather, that it helps people who want to play this role acquire a common set of skills and abilities so they can be recognized, even celebrated.”

It won’t be easy, as Grenier well knows. He recognizes the challenges and vows the project will not lose sight its roots: in mutual empathy and respect for those experiencing mental illness.

He’s keeping that in mind as he plans a three-day research session later in February.

The participants will include 25 people from different areas, including clinicians, researchers, academics and people with lived experience of mental illness.

Their goal is to come up with a preliminary blueprint for the project’s three main areas: standards of practice, curriculum and the research.

“It will be a big milestone to produce those documents,” Grenier says. “Everyone shares the vision of an organic process which is grounded and true to its original purpose.”

Those who have lived with mental illness will serve as the group’s alarm system.

“They’re my B.S. detectors,” Grenier says. “I really trust them to do that.”