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Training needed in "school of hard knocks"

Mental health service providers, from psychiatrists to case workers, need to have, as a formal part of their training, course segments provided by experienced family members and advocates, in the same way they now get training from other instructors.

Or to put it differently: They need to be trained in the school of hard knocks that family members go through.

Without it, they not only remain inadequately trained for some key aspects of their work, they are also going to continue to contribute to system failures, often with punishing results for the mentally ill.

To understand the rationale for this training, one needs first to understand the crucial role that families play in producing better outcomes. One also needs to understand the importance of what qualified family members can bring to the training of others in the field.

Experience, peer programs provide unique knowledge

Take the North Shore Schizophrenia Society as an example. The knowledge, experience and qualifications that derive from the work of NSSS's Family Support Centre represents an important training capacity.

At the heart of this capacity, and the strength of its support workers' professionalism, is the peer principle: All of the people delivering the Centre's core support services are family members with an ill relative themselves.

We use the words "professionalism" advisedly, to describe their qualifications, although there is no B.C. College of Family Peer Support Workers handing out certificates.

Maybe there should be.

NSSS support workers do, in fact, receive formal training. In taking the Family-to-Family education course, they gain considerable knowledge about symptomology, diagnosis, the neurology of the brain, medications and how they work, recognizing and responding to signs of relapse, handling crises, communicating with those who are psychotic, side-effects of medication, the physiological and emotional impact of psychosis, the emotional stages of recovery, and much more.

They also learn key elements of the law dealing with, among other things, involuntary admission, police intervention, and the sharing of information – key elements which, ironically, and sadly, many psychiatrists and case workers get wrong.

Both family peer support workers and Family-to-Family teachers receive more specialized training as well, specific to the work they do – formal training programs systematically covering the field.

What counts more, however, and where they are uniquely qualified, comes from what they have learned in the proverbial school of hard knocks. They have been through it. They know the anguish and trauma of watching someone close to them fall ill with a broken brain.

They learn, too, hard lessons about the obstacles people often face in trying to get proper help for their loved ones.

This front-line knowledge comes not just from their own experience but also from the unique feedback loop of a family peer organization, where family members openly share cases among themselves. These are experiences and details family members would not dare share with psychiatrists or case workers because of the fear of backlash.

They also know the pertinent provisions of the law in a working way rather than in just a bookish, class-room way. They've had to have that familiarity in order to advocate for their loved ones.

Family members, as well, often have a sixth sense of when their ill relatives are deteriorating and the danger they may be in – a sensibility attuned to even the smallest of clues. This is over and above the use of standard diagnostic criteria.

It's why NSSS has found that when service providers and family members disagree about the seriousness of an ill person's condition, the family members are almost always right.

In short, family members, and especially trained peer support workers and Family-to-Family leaders, have a dimension of expertise unique in the field.

Service providers missing this essential background

Service providers like psychiatrists and case workers, unless they have an ill loved one of their own, don't currently have this critical background. They haven't had to study and graduate in the school of hard knocks that family members have been through, and there is no training equivalent.

It shows.

Sometimes even the most sympathetic and knowledgeable professional will say something or do something that makes no sense to family members – that they would never say or do – showing a critical gap in the service provider's experience and a bias in their perspective.

Other times, it's much worse than that – bad judgements; negligence bordering on malpractice; a lack of savvy and realism (sometimes giving the impression they don't know what serious mental illness is); misunderstanding or even ignorance of applicable legislation; condescension, pretension or sheer rudeness; an inappropriate casualness; a failure to follow best practices.

And sometimes their responses can be just bizarre.

The consequences – in preventable suicides, for example – can be tragic.

The *NSSS Advocacy Bulletin* has, over the years, documented such case histories in extensive detail, and despite many improvements and dedicated staff in mental health services, they keep coming up.

There is also little accountability in the system. The handling of complaints by health authorities deliberately avoids holding anyone accountable, with questionable practices usually rationalized away or otherwise whitewashed, something NSSS has also extensively documented.

Most departures from best practices are probably not even recognized.

NSSS has come to the conclusion that, in addition to bringing such issues to the attention of mental health services and the public, the best way of improving practices is better training rather than just more of the same. The key component that's missing is training by family members.

This component is all the more crucial given the growing recognition that family members should be an integral part of the treatment team. Psychiatrists and psychiatric nurses are represented on the faculties of universities and colleges teaching in the field. It's only logical that family members should be represented as well.

Riverview redux, phoenix rising, or lost horizons?

The future of the Riverview Lands is now under discussion, at least in appearance, with an invitation by B.C. Housing to do some "visioning" about how those lands should be used.

Is it going to be (a) the rebuilding of Riverview Mental Hospital (Riverview redux), (b) something new for the seriously mentally ill from out of the ashes of the old Riverview (phoenix rising), or (c) possibilities for the seriously ill lost forever in a scramble to sell off the lands for housing (lost horizons)?

It's a question that NSSS, a defender of the core idea of Riverview, has wanted to have discussed for a long time.

One of the encouraging aspects of the talk to date is that, for all that the old Riverview Hospital has been unfairly maligned, there is widespread sentiment we should take advantage of the lands to provide new facilities for the seriously ill.

Coquitlam, where the Riverview Lands are located, favours such use. Many other Lower Mainland mayors have asked for better housing and treatment of the seriously mentally ill, notwithstanding existing tertiary facilities and newly created Assertive Community Treatment (ACT) teams, and what better place to fill the gap than the Riverview Lands?

There is still some talk of creating a "centre of excellence" dealing with the treatment of the severely mentally ill, despite the fact that specialized, advanced work on mental illness has now been relocated elsewhere.

The sentiment behind Riverview that the seriously ill shall not be abandoned thus remains alive, serving as an inspiration for innovation and creativity for the new site.

On the cusp of something quite innovative and rewarding

We enjoy several advantages over the past when it comes to deciding what to do with the Lands.

First, we're not tied to the old model, before anti-psychotics, when anyone who was seriously mentally ill needed some kind of hospital or refuge.

Second, there is a lot of land available. Given the patterns of population growth in the Lower Mainland and Fraser Valley, the Lands are also relatively central. They include, as well, a unique arboretum – the famous heritage trees.

Most important, we've learned a lot in the last few decades about what works and doesn't work for the seriously ill – the limitations of community mental health teams for those most severely affected, the value of innovations like Assertive Community Treatment, the disaster of deinstitutionalization for its own sake, and much more.

We could, then, be on the cusp of something quite innovative and rewarding.

The City of Coquitlam, in a report almost a decade ago, brought forward some interesting ideas, with at its centre, the premise that "the land should remain publicly-owned to provide a sanctuary and residential treatment facility for people with mental illness."

The report also envisaged research and education in the field, with tie-ins to universities in B.C..

Protecting the arboretum, with the possibility of a horticultural centre and a botanical garden, was another part of the city's vision for the site and remains a priority.

The City also wants to take advantage of the heritage value of the site, including a couple of major buildings that are still viable.

We need at the same time to recognize, however, that the scale of operations that benefited research in the old days is gone.

So where do we go from here?

There are already two tertiary residences at Riverview and a tertiary rehabilitation unit. These components could be expanded, together with long-term residences for those unable to manage more independent living.

This constellation of elements could become, in turn, a new centre of specialization and research.

Refractory (B.C. Psychosis) could be relocated back to Riverview, from UBC.

Let's, however, take full advantage of what lies before us – a kind of "green field" for a new project.

Deinstitutionalization to date has meant moving people into existing communities, with support to help them grow and participate, with variable success.

Rather than having the most seriously ill fit into communities, however, why not, at Riverview, build a new community that fits the seriously mentally ill instead?

Why not, so to speak, stand deinstitutionalization on its head?

Whatever happens to the new Riverview, then – horticulture, non-profit ventures, research, an artist's colony, mixed housing – working with the seriously mentally ill and helping to support a more self-reliant community of the mentally ill will be part of the mandate of activities which locate there.

It won't be easy and won't be without serious challenges. The people currently living in the three locations at Riverview, and those yet to come under this scenario, are those who have the most difficulty, sometimes for managing even ordinary tasks.

And perhaps the best option in the end will be just sanctuary.

We should,, though, as part of this "visioning" process for Riverview, at least explore what a larger community would look like where the seriously mentally ill have pride of place but aren't alone.

Let the discussion begin.