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Progress is being made, but oh so very slowly

The introduction of Assertive Community Treatment teams (ACT teams) in British Columbia is a major step forward. It reflects a recognition that de-institutionalization without something equivalent to intensive hospital care in the community has been a failure.

A full-size urban ACT team consists of a multi-disciplinary group of 11-12 service providers, including a psychiatrist, providing the same kind of care for the most severely mentally ill as they would receive in a continuing stay in a mental hospital like the former Riverview.

Indeed, an ACT team is sometimes described as a hospital without walls.

The team has someone available 24 hours per day, 365 days a year, for crisis support, just like a hospital. Team members visit each patient on average three times a week, but multiple contacts may be as frequent as two or three times a day, depending on the situation.

The team also administers medication, with a goal, however, of the patient managing their medication on their own.

Ideally, all the other kinds of support are provided as well. Our favourite example is the case in Ontario of a woman going to spend Christmas day with her family. An ACT team member helped her fix her hair, just as a psychiatric nurse or ward aid might do if the patient were in hospital.

This small act of support underscored how intensive, and comprehensive, care and monitoring by an ACT team could be.

Recent heightened concern spurs government action

There are now reportedly 14 ACT teams in B.C., and two more will be added as part of a new “action plan” announced by the provincial government.

The government’s announcement followed heightened concern by several Lower Mainland mayors who had lost patience with the status quo.

Too many seriously mentally ill were being prematurely released from hospital, or their lack of insight – anosognosia – meant they weren’t taking their medication and were quickly becoming ill again.

Those with a concurrent disorder – mental illness and substance abuse both – were particularly left to deteriorate and suffer, and be preyed upon. The Downtown Eastside symbolized it all.

Vancouver mayor Gregor Robertson and Vancouver’s police chief Jim Chu have been especially outspoken. The Vancouver Police Department had earlier done two critical studies on the situation. Vancouver, through the mayor’s office, has set up a task force on the mentally ill.

Some of the mayors would like to see a new, modern hospital at Riverivew, on a smaller, more specialized basis, to provide a home for the relatively small number of mentally ill who need such closely supervised care - care that even ACT teams cannot adequately handle.

The establishment of ACT teams, nevertheless, does address helping the most seriously ill who have borne the brunt of deinstitutionalization’s failure. This isn’t to mention the many who didn’t survive.

Encouraged as we are, we still can’t help asking the question, “What took so long?”

“Madness in the streets,” to borrow from the title of a bellwether book on the subject, isn’t a recent phenomenon. It goes back virtually to the days, thirty or forty years ago, when serious deinstitutionalization began.

It was clear almost from the start that while anti-psychotic medications meant many mentally ill could do well in the community, and that community mental health teams could support them, for the most seriously ill that wasn’t enough.

The Downtown Eastside quickly became notorious for our society’s

disregard of the victims of deinstitutionalization, nor was it the only area in B.C. where the damage showed itself.

The gap between the downsizing and closing of Riverview, on the one hand, and the inability of community mental health to adequately look after the most seriously affected, on the other hand, wasn’t just a crack in the system, it was a chasm.

First ACT team in B.C. not established until 2008

Nor is the ACT team model, which could have dealt with this, something recent.

Ontario established its first ACT teams, on an experimental basis, in the late 1980s.

NSSS has long been advocating for them in B.C.

The model, in fact, has been available since it was created, in Wisconsin, in the early 1970s

Yet it wasn’t until 2008 that the first full-fledged ACT team was established in the province, in Victoria, and not until late 2009 that Vancouver had its first proper ACT team. Why did it take 35 years just to get to that point?

The same question arises with regard to homelessness and the mentally ill. Why has it taken until now for the issue to get the attention it needs? The connection between proper housing and helping to produce better outcomes for the mentally ill was already known when deinstitutionalization began.

One additional aspect also needs to be taken into account. No matter how effective ACT teams and additional housing will be, there will always be a small group of mentally ill people who are so ill, and relatively unresponsive to treatment, they will require long-term psychiatric residence – asylum, in short.

We shouldn’t oversell ACT for them.

We need to make sure they have a place to live where they get the supervision, care, support and security they need.

Progress also made with info sharing

Sharing clinical information with family members is another area where progress is finally being made.

Last September, Vancouver Coastal Health's mental health and addiction services issued a new policy supporting family involvement.

Lip service has been given to family involvement for a long time, but as the *NSSS Advocacy Bulletin* has pointed out in the past, the inclusion of family members as part of the care team doesn't mean much unless there is information sharing as well.

The new policy appears to take this into account.

We say "appears," because the policy statement still raises questions.

The document states that service providers "are encouraged and allowed to share as much information as possible recognizing the guidelines of B.C.'s privacy legislation."

Later on it refers to "the ability to share necessary information with family members...for continuity of care and to address safety concerns."

The question that needs to be addressed directly, though, is what to do when the patient is psychotic and paranoid or otherwise won't give consent for information to be shared. Those are times when bringing family members into the loop is probably most important.

One has to go to a "Questions and Answers" secondary document for an answer.

"In the absence of consent," this second document reads, "...care providers may share with family members who are within the circle of care information they need to provide care, such as behaviours, medications and possible side-effects."

This is a step forward for Vancouver Coastal, although it still falls short.

It doesn't, for example, mention the sharing of information with family members as a way to get feedback and help them – the service providers – do their job.

It doesn't say, either, that information should generally be shared with family members in the same way that service providers, say a psychiatrist

and a case worker, share information between themselves, although this logically follows from the premise that family members are to be an integral part of the treatment team.

The document also lays out rules for asking for consent when the issue of consent shouldn't arise, as it doesn't arise among service providers themselves. The ability to share relevant clinical information with involved family members should be assumed.

The stated guidelines for consent can also be interpreted in such a way as to impede information sharing in some cases.

Still, the new policy and its attached guidelines do, for the first time, spell out clearly that information can be given to family members without consent, at least within the framework provided.

For Vancouver Coastal Health, that's revolutionary.

The legislation which makes this sharing of information possible, the Freedom of Information and Protection of Privacy Act (FIPPA) was passed in 1992. It has taken Vancouver Coastal just 21 years to acknowledge what only made sense from the beginning.

Yes, progress can be oh so slow.

Fuller Torrey book a cautionary tale

E. Fuller Torrey's new book, *American Psychosis: How the Federal Government Destroyed the Mental Illness Treatment System*, reads like a horror story of everything gone wrong.

It describes how the creation of community mental health centres (CMHCs) by the U.S. federal government, led by John F. Kennedy, with high hopes of giving the mentally ill their place in the sun, destroyed the treatment system for mental illness instead, with tragic results.

The initiative, in the early 1960s, coincided with the demonization of state mental hospitals, many of which were "snake pits" badly in need of reform.

The leaders of the CMHC movement hated the state hospitals – wanted to shut down "those goddamn warehouses," as one account at the time put

it. They didn't want the new federal money going to the state systems, either. They ignored the state hospitals instead. There was consequently no linkage between a patient being discharged from hospital (state jurisdiction) and the community treatment centres (federally funded).

The state governments, meanwhile, seeing the federal government moving into their field with federal money, were only too glad to let them have the territory and accelerated the downsizing of their hospitals.

The federal CMHCs, for their part, were misconceived – had illusions about preventing mental illness, downgraded the need for clinical treatment, and suffered from poor oversight as well. They eventually were put out of business, by the Ronald Reagan government in 1981.

At the same time, legal obstacles to involuntary admission had been thrown up across the U.S.

Fuller Torrey calls this combination of factors "the perfect storm," with almost everything at play militating against the treatment of the seriously mentally ill and leading to their abandonment to the streets..

The dysfunctionality of all this, in the U.S., with its bizarre and tangled complexity, boggles the mind.

We avoided many of these problems in Canada because provincial governments had straightforward administrative responsibility.

What we haven't avoided, however, is some of the misconceived thinking underlying the American disaster – the notion, still floating around, that involuntary admission should be limited to cases of overt dangerousness, for example, or that serious mental illness, diseases of the brain, can be prevented by social improvements.

Nor have we avoided the downplaying of the seriousness of serious mental illness and the diversion of funds and attention to "feel-good" programs that should be going to the treatment of the severely ill instead.

Fuller Torrey, on this particular aspect, argues that "mental health centres" should be renamed "mental illness centres," so they don't lose their focus on whom they should be helping and the kind of help they need.

Whether one agrees with him or not on that one, one understands only too well why he is making the point.