NSSS ADVOCACY BULLETIN
Vol. 1, No. 2 February 2009

The woman known as Tracey dies needlessly

The death of the woman known only as Tracey, last December, when candles she lit to keep warm set her makeshift shelter on fire and burned her to death, shows how little progress we've made in helping many of the mentally ill.

Tracey was almost certainly mentally ill, yet the provisions in law that allowed her to be protected weren't enough to save her.

If you recall the story, Tracey had refused to go to a shelter, despite the bitterly cold weather, ostensibly because most shelters had a policy of not allowing people to bring their shopping carts in with them. All of Tracey's worldly belongings were in her shopping cart and she didn't want to lose them.

A phobia about being in a crowded shelter with others was suggested as another possible reason.

The debate that arose after her death centred around these matters. "Should the police be given the power to force the homeless into shelters?" was the question cited in headlines and editorials.

The lack of housing also came into it.

What, however, about her illness, and the lack of insight and judgement that came with it, and the corresponding duty of the health system in particular to help her?

We, at NSSS, can't say for sure she had a "mental disorder" – the requisite for emergency action to be taken under the Mental Health Act. We don't have access to her medical history or even her last name. There's every indication, however, that she was ill.

Why else would she be on the street? Well people do not usually choose to be homeless beggars, nor to refuse help in sub-zero temperatures. Many of the homeless who refused to go to shelters in the cold spell even declined to accept extra blankets.

A homeless neighbour of Tracey's described her as schizophrenic.

Avoidance of shelters, because they're so crowded and noisy, doesn't necessarily come from a specific phobia, either. Schizophrenics in particular avoid crowds, because of the sensory overload and often because of paranoia.

Judy Graves, housing advocate for the City of Vancouver, who knew Tracey, was close to the mark in identifying mental illness as a likely factor in Tracey's behaviour.

"If mental illness is the barrier, that's not something we can overcome with a physical structure. No matter what we do, there'll be a few people who stay out.

"It's important not to listen so much to what they say – 'I choose to do this' - but to listen behind their words and watch their behaviours and understand why they choose to live outside because nobody in their right mind chooses to live outside in weather like this.

"Often the tougher the person looks, the more fragile they are inside. It's really easy to miss that."

Why were the signs missed, or if not missed, set aside?

From the information available to us, then, NSSS has to assume that Tracey was suffering from a mental disorder. As such, police could have intervened to take her to hospital for an assessment if, for nothing else, to ensure her safety from the cold.

The enabling clause in the Mental Health Act is Section 28(1).

Whether the police have the skills or not to pick up the clues of mental disorder, however, they're discouraged from acting under Section 28 except in the most obvious cases, because the mental-health system keeps putting people they've taken to hospital for help back on the street before they're stabilized.

The problem was amply documented in a study done for the Vancouver Police Department by Detective Constable Fiona Wilson-Bates, "Lost in Transition: How a Lack of Capacity in the Mental Health System is Failing Vancouver's Mentally Ill and Draining Police Resources." (The study is available on the web at http://vancouver.ca/police/Whatsnew/lost_in_transition.pdf.)

Police officers, too, may not always be aware of the latitude Section 28 gives them. A person with a mental disorder can be taken to hospital for an assessment if they are "likely to endanger" their safety or the safety of others. The person doesn't have to be dangerous at the moment – wielding a knife or gun, or with a lighter in their hand threatening to set their clothes on fire.

Ultimately, however, it's the health-care system that must bear the responsibility for the plight of people like Tracey.

The capacity problem has long been recognized, at least by those of us who advocate for the mentally ill.

The system has backed up. The radical downsizing of Riverview has put extra pressure on acute care wards, which in turn has put an added burden on community care, inadequate for the severely mentally ill to begin with.

There is no proper assertive community outreach to help people like Tracey.

Lack of capacity isn't the only problem, though, attitude is. All too many psychiatrists and other service providers cite "dangerousness" as a requirement for committal, which is simply incorrect. It's a mistake that's so fundamental that it can only be described as incompetence.

The BC Mental Health Act is quite clear on the subject, allowing for involuntary committal of someone with a mental disorder "to prevent... substantial mental or physical deterioration or for the protection of the person...."

If Tracey had a mental disorder, which seems to be the case, then she certainly qualified for committal and treatment.

Our mental-health system owed her that protection.

She didn't get it.

Direct advocacy to improve system

North Shore Schizophrenia Society and Joanne Bezzubetz, director of Mental Health Services for North Shore and Sea to Sky, have established a line of communication to deal with system problems that family members bring to NSSS's attention.

Under the arrangement, NSSS makes submissions directly to Bezzubetz, who reviews them and then forwards them to her staff for investigation and for remedial action where called for.

The arrangement arises from a recognition that the feedback families have to offer is essential to helping improve the delivery of mental health services.

The particular value of the NSSS submissions is that they come from an organization outside "the system," hence with an independent voice. They reflect the viewpoint of those closest to the individuals whom the system is meant to serve.

NSSS at the same time, being a peer organization, hears things from family members that they are reluctant to disclose to service providers, for fear of backlash again their ill loved ones.

The NSSS reports also benefit by the range of work its Family Support Centre does and the Society's collective 25-year history, which bring knowledge, context and understanding to the discussion of issues.

The result is a frank look at system problems, together with recommend-dations for improvements, that otherwise wouldn't be available to system managers.

Information included in the NSSS briefs has the prior agreement of the family members involved.

The director of Mental Health Service's open door is a promising new development that marks a shift from previous attitudes.

NSSS submissions to date have outlined actual case histories, followed by a listing and analysis of the issues raised – issues that often have a wider application. The reports are usually done after other avenues have been tried without success.

NSSS also helps family members write letters of their own, if they prefer to take that route.

Both the organization's submissions and the help given to individuals in formulating their own comments are part of NSSS's larger advocacy effort stemming from what family members regularly face on the front line in trying to help their loved ones.

FEEDBACK WELCOME

We welcome your comments on anything you read in the Advocacy Bulletin. If you have a story of your own about struggles with the system or short-comings that need to be remedied, and would like to tell us about it, please also get in touch. You can drop by the Family Support Centre, call us at 604-926-0856, or send us an email at advocacy@northshoreschizophrenia.org.

Information can be shared with family members

Both Ontario and BC privacy commissioners, in a joint message, made it clear that information about a patient's mental illness may be shared with family members.

The statement was issued last year, but is worth noting again because of continuing claims by mental-health service providers that they cannot, in law, disclose information to families because of privacy considerations.

Those claims are mistaken, something NSSS has pointed out again and again, but it's as if BC's actual privacy legislation doesn't count. The claims are made regardless.

Trained professionals, however, should know better.

The upshot is that the well-being of the mentally ill is compromised. Family involvement in the treatment process and in post-discharge management, which produces better outcomes, is undermined when information isn't shared.

The safety of the mentally ill is also compromised if family members, who are often in the front line, aren't fully informed about their ill relatives' symp-toms, diagnosis, medication, and severity of illness.

The privacy commissioners' message – by David Loukidelis for BC and Ann Cavoukian for Ontario – was made in the shadow of two tragic incidents, the suicide of Nadia Kajouji, a student at Carlton University, and the Virginia Tech massacre, which might have been averted had information been shared with family and also, using common sense, with school officials.

Privacy laws are not to blame, the commissioners stressed, because they do permit disclosure.

The commissioners' statement brings to mind a previous tragedy here in BC, where, in 2004, an 18-year-old UBC student from Portland, Stephanie James, committed suicide on a second attempt a month after she had first tried and been hospitalized. Neither Vancouver Hospital nor UBC, however, had informed Stephanie's mother, in Portland, of the first attempt because Stephanie didn't want them to. Had the mother known, she would have hurried to Vancouver to give her daughter support and, quite possibly, Stephanie would be alive today.

The Stephanie James case and some other local cases, where the withholding of information from family members ended with tragic results, are documented on the NSSS website. See the "Information Sharing" page and click on "case histories."

There's also a link from that page to the Ministry of Health Fact Sheet on the issue pointing out that information can be shared not only to protect someone who is mentally ill from risk but also for "continuity of care" – in which role family members are usually key players. This can be done even without the permission of the patient, in the same way that information is shared among psychiatrists and nurses.

One is led to speculate that professionals who cite privacy legis-lation as an excuse not to share information do so because, behind the excuse, they do not want to admit that family involvement is important and to engage family members as "therapeutic partners." This resistance to family involvement also runs against best practices.

NSSS, in its support and education work, takes care to let family members know that information can indeed be shared with them and they should actively pursue such information-sharing, even if their ill relative, like Stephanie James, doesn't give permission.

Anything else is to hurt the mentally ill rather than help them.