

Oct. 22, 2018
 Pathways SMI letter of concern addressed to:
 Standards Associate - Health Standards Organization (HSO)
 Ottawa, Ontario.
 Attention: Carolyn Wayne

Dear Ms. Wayne,
 Since its founding in 1995 Pathways Serious Mental Illness Society, formerly North Shore Schizophrenia, has been supporting families challenged in accessing adequate treatment for their loved ones and actively advocating for the best services for those with severe mental illnesses and the families who support them.

We are writing to express our concerns about aspects of the HSO’s new Mental Health Services standard in that the vision of recovery that it promotes doesn’t appear to take into account the needs of people with the most severe mental illnesses. If it is enacted, people with psychotic disorders and their families may face even greater challenges.

Of greatest concern: The undermining of involuntary treatment. “Recovery must be accomplished using the client’s choice of services....”

It would appear that the standards have not considered the most

common symptom of psychosis; “anosognosia”, a biologically based inability to understand that they are ill.

When people in psychosis don’t have access to involuntary treatment, they remain trapped in a vulnerable condition that prevents them from understanding the world around them. Pathways agree clients should participate in all decisions that impact them; however here is the caveat, when they are able to do so. In some areas, half of the hospital admissions are involuntary where patients cannot direct their treatment, having neither the insight nor capacity to do so. The standard should ensure that facilities licensed to admit and treat involuntary patients have the appropriate number of staff with the appropriate skills. These facilities should offer rights protections and recovery-oriented activities. B.C.s Mental Health provides an excellent standard for involuntary treatment.

To ensure the Standards include evidence based treatments for people with severe mental illnesses:

People with severe mental illnesses should have access to programs that are established evidence-based treatments. Cognitive losses are a common and well-researched feature of these illnesses, and so these and other services should include

access to cognitive assessments and cognitive remediation services; programs such as psycho-education that provides them with information that allows them to understand and learn to manage their illnesses People with psychotic illnesses should not be exposed to services that are not evidence based. Our caution is programs that are not evidence based, and therefore less costly, will potentially undermine medically necessary treatments.

To ensure that the Standards address the well-researched prevalence of relapse:

Extensive research lets us know that a major issue in the relapse of people with psychotic disorders is the discontinuation of necessary medications. We recommend that the standard directs service providers to have plans to prevent relapse due to discontinuation and procedures for detecting and responding to relapses. We do not believe that untreated psychosis should be viewed as an option any more than cancer or any other illness.

Better education on Family Engagement for clinicians:

Mental illness is at an epidemic level and health systems require everyone at the table. We’re pleased that the standard does emphasize cooperation with families. However, it only recommends this if the client agrees. Mental illness tears families

apart and a standard where family education and involvement in the treatment plan is endorsed as a priority reflects a true acknowledgement of the reality for many people with psychotic disorders.

Paranoia is a common feature of psychosis and when people emerge from psychosis, they may need a lot of help in rebuilding relationships with their families. Clinicians are not currently trained to offer this kind of assistance and, unfortunately, too often undermine clients’ relationships with their families. Even when clients are not prepared to include families, family caregivers should be encouraged to provide crucially important information to service providers about how a client is actually doing. This information is essential in making the best medical and psychosocial rehabilitation decisions. Vancouver Coast Health has a progressive approach to family involvement in all cases.

Of grave concern, putting additional responsibilities on families:

The standard suggests that families should be trained to handle violent situations. Families do receive training in avoiding and de-escalating tense situations when they take the kind of family psycho-education courses which Pathways offers: Family-to-Family Education. However, families should not be expected to handle violent behavior; they should have easy

access to emergency services that can respond to these situations.

Peer services – a lack of education, and supervision, at what cost:

Pathways values and supports the appropriate use of peer workers. It is also critical that peer workers are properly trained and understand the illnesses of the people with whom they are paid to work. The Canada’s national guidelines for training this work force do not recommend that peers learn anything about mental illnesses leaving the peer work force inadequately prepared to understand and provide the best assistance to the people they work with. We believe standards should support the need for this basic training along with professional supervision. Our greatest concern with the peer to peer model, with the population we support, is that they are not being treated by clinicians with the most extensive training.

In closing we would appreciate clarification with respect to the following two questions:

1. Why were these standards developed without input from psychiatrists? People with serious mental illness require psychiatric treatment, specialists, just as you would expect for diabetes or cancer. Our families and their relatives depend on these

specialists to establish and maintain stability. Psychiatrists whose work includes substantial contact with people with severe mental illnesses would have brought relevant experience to the preparation for these standards.

2. Have these standards been sent to the Canadian Psychiatric Association for their input?

We appreciate this opportunity to share our experience with you. We look forward to your response to the two questions posted and we trust you will keep us informed about any revisions to the national standard for delivering mental health services.

Pathways ED and Board of Directors

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November 2018 update – Pathways has been informed that the Standards are being reviewed by a psychiatrist.