

PRESENTATION TO STANDING COMMITTEE ON HEALTH RE BILL 52

Good morning Mr. Horne and ladies and gentleman of the Standing Committee on Health:

My name is Tom Shand and I am Executive Director of the Alberta Division of the Canadian Mental Health Association.

Thank you for providing this opportunity to speak with you today on a very important subject – the sharing of one’s personal information, as reflected in the proposed Bill 52 – the Health Information Amendment Act, 2008.

I am here today speaking not only on behalf of the Canadian Mental Health Association, but more importantly in the interests of the hundreds of thousands of Albertans currently living with mental illness or who will experience mental illness at some point in their lives. Although it is not the type of illness for which it is possible to obtain an exact number as to how many people fall within this description at any point in time, it is conservatively estimated that it includes at least one in five Canadians, which would equate to more than 600,000 people living in Alberta.

Although many of my remarks will apply to others as well, I will focus on putting forward a perspective reflecting what we know of the needs and concerns of many of those living with mental illness.

As I expect is likely the case with the majority of those presenting to you, I am not here to suggest that electronic record keeping does not have value. Clearly, we recognize that Albertans living with mental illness also require physicians and other caregivers to have accurate, relevant information available to them on a timely basis when seeking to make a diagnosis or to effect treatment.

However, there must clearly be a balance between a person’s right to privacy and the need for sharing of their personal information for medical reasons. We believe that Bill 52 has exceeded that balance at the expense of the individual’s right to privacy. Over the next few minutes, I will outline our greatest concerns as well as what we believe could be the consequences should this Bill be passed in its present state.

We have not sought to analyse the wording of each clause or to suggest alternative wording. Rather, I will try to express our concerns in the most clear-cut manner and leave it to your resources and expertise to determine if a given clause should be removed or revised.

As is no doubt the case for most of us in this room, sharing personal information relating to one’s health is a very private matter. It is not done lightly and most often with only very few people, including one’s physician or medical team. With this group, there is a trust that the information shared will be kept in confidence and only given out on a need-

to-know basis to a very restricted circle. Further, it is expected that, should requests come from outside that circle, the individual should have the right to deny permission for access to information not absolutely required or, at the very least, be provided knowledge of what disclosures were made and to whom.

For many, even this very limited sharing of information is not comfortable and any breach of this trust or confidentiality is not soon forgotten. Even if nothing untoward results as a result of this sharing of information, there is a grave risk that the trusting relationship with the caregiver may be damaged perhaps irreparably.

And that is the situation for most people. But for a person who has been treated for mental illness, the potential downside is far, far greater.

For starters, the comfort level for sharing information about their mental illness, either past or present, is much less. Saying that you were treated for depression three years ago is far removed from saying you broke your leg skiing. It is not unusual for a patient to fear stigma and potential for discrimination resulting from disclosure of treatment for a mental disorder for the rest of their lives, even if the person is in perfect health now.

Unfortunately, the risk of stigma and discrimination relating to mental illness is real – in the workplace, at school, amongst one's family and friends, with housing, insurance – and the list goes on. There is good reason that the Mental Health Commission of Canada has made reducing stigma relating to mental illness a top priority and that organizations such as the CMHA are continually fighting that same battle. Reducing stigma and discrimination is a very real and very important step in assisting people living with mental illness to be able to effectively seek treatment and achieve optimal recovery.

It is difficult enough to discuss very personal mental health issues, either your own or those of family members, within your small circle. It is an entirely different matter knowing that those records can be accessed by 26,000 or more people. And worse yet, that your physician may be forced to divulge information beyond absolute need or that there is not even complete control as to who will be able to access those records down the road. And worse again, that you will be helpless to control the process or even discover who is accessing those records.

Clearly those risks, or even the possibility or perception of that lost privacy, are not warranted or justified. Even if there are no abuses or system breakdowns that cause harm, the realization that such a possibility exists will be harmful – and even more so for those amongst us who have increased sensitivity about others negating their right to privacy.

For many people, particularly those needing treatment for mental illness, the result will be that they will not divulge certain medically relevant information to their caregivers or they will not seek treatment at all. This would be catastrophic and unto itself reason enough to change the parameters of this bill.

To help alleviate these concerns for unreasonable invasions of privacy, we would recommend the following:

- Put in place appropriate safeguards such that information shared is limited to that information absolutely required and by those with an absolute need to know in the best interests of care of that patient.
- That physicians and caregivers not be forced to comply with providing information, beyond what they deem as required.
- That the ability to mask unneeded information be maintained.
- That use of information continue to be seen as disclosures and that the patient maintains the right to review such disclosures.
- That individuals may appeal what is on their record and how it is used.
- That records be not sold or otherwise made available to outside sources, e.g. employers, employee benefit programs, insurers, justice system, law enforcement, etc., without the expressed consent of the individual or by subpoena or other form of legal review.
- That the Bill include enough restrictions regarding uses and users to ensure that necessary safeguards are in place and that such restrictions are not trusted to the regulations which are too easy to amend, at a later date, without adequate discussion or consultation.
- That extensive public consultation take place before consideration be given to a Bill that has the potential to seriously jeopardize one's privacy.
- That Netscape or any other means of gathering and disseminating electronic patient records be thoroughly examined on an ongoing basis for potential flaws or leaks.

In essence, this amendment has taken something that is essentially a good idea and wrecked it.

I do not know whether this amendment is salvageable or if it's back to square one, but I am positive that this Bill, if left as proposed, is bad for Albertans and particularly those many Albertans living with a mental illness.

Thank for your consideration.

Respectfully submitted,

Tom Shand

February 4, 2009

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