

BRIEF TO THE “PATIENT FIRST REVIEW”

by the

Canadian Mental Health Association (Saskatchewan Division) Inc.



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Saskatchewan has had a long, and sometimes checkered history when it comes to mental health services and empowerment/support of mental health consumers and their families.

As late as the early 1990's there were mandated and supported consumer and Community Based Organization (CBO) advisory groups meeting on a regular (monthly or quarterly) basis in most, if not all regions of the province.

With the advent of the “wellness model” in the mid-nineties and the resulting decentralization and “integration” of mental health into the larger health system, these groups gradually disbanded and the empowerment and “voice” they provided to the system was lost.

The following brief makes the point that, as is emphasized in “Out of the Shadows at Last”, mental health consumers are often more impacted by the stigma and lack of community, and often professional, understanding of their mental health issue than they are by the mental health disability itself.

It is absolutely critical for the “recovery” of persons with mental health issues that ways to give “voice and influence” (i.e. empowerment) to consumers and their families be found and incorporated into our formal mental health system.

This brief is based upon several documents which represent a tremendous amount of work and time regarding mental health issues. These documents include “Out of the Shadows at Last”, “A Recovery/Resiliency Plan for Mental Health & Addictions in Saskatchewan” and “Results of the Canadian Mental Health Association (Saskatchewan Division) Inc. Consumer In-Patient Survey”.

The main thrust of the sections of these key documents is that mental health “consumers” and their families, and by extension the very services which provide for them, are all negatively impacted by the stigma and resulting discrimination it leads to.

The “Recovery Model” has as one of its main tenets the principle of consumer and family involvement as a key part of the philosophy of “Recovery”.

It is hard to imagine a group of patients more stigmatized and disempowered than those with a serious mental health and/or addictions issue.

"I felt condescended to, and belittled by many of the doctors I came across in the mental health system." – Lisa

"I have waited in an Emergency Room for as long as 6 hours, in a suicidal state, while others with physical ailments have proceeded ahead of me.

The person at the desk who filled out the necessary paper work was informed of my condition. Yet in spite of this, I was made to wait as another incoming patient had physical signs of distress, blood, broken bone." – Anita

"The health care profession is not very comfortable with any one of its own having a mental disorder. It is kind of a "not in my back yard" attitude. Once labeled as damaged, that worker should go "somewhere else," not remain in this workplace"

– Sheila Hayes Wallace

Quotes taken from "Out of the Shadows at Last – Transforming Mental Health, Mental Illness and Addiction Services in Canada"

Final Report of the Standing Senate Committee on Social Affairs, Science and Technology, The Honourable Michael J.L. Kirby, Chair, May 2006

Studies and reports have shown that systemically, caregivers of those with mental health and addictions issues have built into themselves and the services they provide society's misconceptions regarding mental illness

It is for these reasons that ongoing and supported consumer and family involvement in review of policy and procedures of inpatient, day program and emergency room services are critical to ensuring a balance of societal, professional and patient needs are met.

The following highlights from "A Recovery/Resiliency Plan for Mental Health & Addictions in Saskatchewan" pages 15-27 underline the importance of this input.

Consumer Involvement and Initiatives

The Benefits of Consumer Involvement

According to one report (Canadian Mental Health Association National Consumer Advisory Council, 1993), some of the reasons for involving consumers in all areas of mental health are:

- Consumers speak from experience and can offer new ways of looking at things from that vantage point.
- Consumers must participate as paid "peer support" as a growing peer support movement shows the tremendous value this provides as an integral part of the recovery movement.

- Consumers' input is as valuable as that of professionals and family members.
- Consumers get the attention of politicians and funders.
- Consumer involvement will make policies, activities and processes more relevant and rooted in reality.
- Expertise in organizations is more diversified with consumer involvement.
- The present mental health system needs improvement, and new expertise can help.
- Consumers are a credible voice – involving them is in keeping with both federal and provincial governments' conviction that people with disabilities can and should speak for themselves.

Family Support and Involvement

Mental illness in the family creates a crisis that affects all members. The chronic stress family members experience in their new role as primary caregivers dealing with mental illness often undermines their own health, financial resources and ability to cope. This negative effect on the family unit can also hinder the stabilization and rehabilitation of the person with mental illness.

Training in coping skills, communication, information and support reduces the level of crisis in families, as well as reducing the relapse rate of the patient. In addition, the way families are treated and supported can contribute to the rehabilitation of the patient.

The 1993 report of the Task Force of Families and People with Mental Illness, "Families Sharing the Caring", noted that unrealistic expectations were placed on family members, who were often expected to advocate and provide services that should be provided by the system. Confidentiality was cited as a frequent barrier to effective communication and support.

The task force recommendations form the basis for best practices in family support and involvement, which have been endorsed by family groups throughout the province. Best practices for family support and involvement include:

- Provision of professional counseling for family members in need, including assistance in accessing services – Case Managers should provide family members with information, support and coping skills.
- Partnerships among families, consumers and professionals in the treatment plan – Families must be informed and aware of the treatment plan and discharge planning should focus not only on the individual's personal functioning, but also on the family's ability to care for the client.

- Inclusion of families in the planning and evaluation of services – Family members want opportunities for their voices to be heard and for input into planning and evaluation.
- Expansion of training to mental health professionals to include skills and competencies that would increase their understanding and improve their ability to meet the needs of families – A more comprehensive professional education program for mental health service providers will enhance support for families.

The working group also recommends that a family and consumer forum occur twice a year for two days to review consumer and family issues that are systemic in nature. The forum could monitor implementation of the mental health plan using the best practices models.

Adapted from “Best Practices in B.C.’s Mental Health Reform”

The following recommendations are taken from the “Conclusions and Recommendations” section of the “2008 CMHA Consumer Inpatient Survey” and are based largely on well recognized practices, which in our opinion are among “best practices” from other jurisdictions which have moved to a “recovery-oriented” philosophy and practice model.

Recommendations:

1. Consumers must be more involved in their care, including having more education about treatment options available to them.
2. Prior to coercive measures being taken, practitioners should relentlessly try different ways of engaging and persuading individuals in ways which respect their ability to make choices.
3. Practitioners should encourage individuals to write their own crisis and contingency plans, with education of options and support from professionals, when the individual is in an appropriate state of mental wellness.
4. There should be, with consumer input and influence, the development of crisis plans employing a progression of interventions designed to de-escalate volatile situations.
5. There should be education for staff and consumers regarding the use of Psychiatric Advanced Directives, which incorporates the principle that constraint of individuals presenting clear threats to their own or others safety and welfare, is guided by both individualized plans and agency policy.
6. There should be implementation of a “shared decision making” process, which would go a long way towards empowering consumers to be more involved in their care. This is a process in which the treating physician and the consumer explore treatment alternatives available to them. This allows a mutual blending of the “expertise in the science-informed process of medical diagnosis and treatment” while the consumers bring with them the

“expertise of the lived experience” (Deegan 2007, p.64). This process ensures that the consumer is presented with all treatment options available to them and offered alternatives if they disagree with any treatment recommendation. This may need to be suspended if the person is very ill, however, this is where the Psychiatric Advanced Directives become relevant and would be employed.

7. Finally, and very important to put meaning to the above, is the involvement of both consumers and their families in continuous, system-wide quality improvement plans. Input into standards at the systems level would go very far in creating a more effective system. This is considered an important system level standard in the design and evaluation of recovery-oriented mental health services (Anthony 2000, p.164).

A very important, and historically significant systems point (one that has been reinforced over and over again by the Romanow, Fyke, Kirby and other reports) is that the mental health system has not been funded adequately and has not kept up with the other parts of the health system. Without some recognition of this, and real, significant resources put in place to rectify this, it gives very hollow meaning to best practices like “looking at all alternatives for treatment”, as there usually are not those alternatives to look at.

We seriously hope that “Patient First” looks at the big picture problems outlined above, and not just the discrete, smaller pieces of the puzzle.

Respectfully submitted,

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